

**Alignment of patient and provider views in health care intervention
programs: A study of the Centre for Healthy Active Living at the Children's
Hospital of Eastern Ontario**

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Abstract

This research study focuses on examining the views of patients, their families, and staff member providers of the Centre for Healthy Active Living a clinical obesity management program for children and youth at the Children's Hospital of Eastern Ontario, in Ottawa, Canada. Qualitative methodology was used and content analysis was conducted with data obtained from family questionnaires and a provider focus group. Analysis of obtained data was conducted to determine alignment of views between patient, family, and provider views, and the formal goals of the program. Emerging themes from the data indicated that patients and families place higher value on the formal goals of "improve quality of life; improve eating behaviours; improving fitness, increasing activity levels; and empower/strengthen families." (Children's Hospital of Eastern Ontario, 2012). Specific recommendations with regards to each component of these goals were provided. Instrumental, procedural, systemic, and conceptual recommendations of program components were also provided.

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1. Introduction

Clinical obesity is a condition that is affecting increasing numbers of people in Canada, and around the world. The easy availability of calorie dense foods and the increase towards a sedentary lifestyle are factors which greatly contribute to this epidemic. According to the Food and Agricultural Organization of the United Nations, more people around the world are overweight and obese compared to those who suffer from hunger (2012).

One group that is particularly vulnerable to the condition of clinical obesity is youth. Youth are growing up in an environment where consuming quick, calorie dense food is the norm, and where hobbies and activities increasingly involve sedentary behaviour and screen time. Under these conditions, those youth who have a genetic predisposition towards obesity, and those who have other risk factors such as parents who are obese, are more susceptible to succumb to the disease (Bottcher, Korner, Kovacs, & Kiess, 2011).

In order to treat clinical obesity, a number of clinical obesity management programs have been developed to treat the most severe cases of this condition. These clinical obesity management programs include a medical assessment component, as well as a behavioural therapy component to address the varying facets of this condition.

In healthcare, it is important that there is alignment of views between what a patient expects in terms of their treatment plan and anticipated outcomes, and what the expectations are of the practitioners who are treating their patients. There should be general agreement of expectations, to maximize the benefit that the patients gain from the program (Heisler et al., 2003). This is especially important in programs which have a behavioural therapy component, such as smoking cessation programs, and obesity management programs (Foster, Makris & Bailer, 2005). In these instances, the behaviour of patients and their willingness to change has a direct impact on the outcomes of the program; patients and providers must come to an agreement in terms of expectations of this anticipated behavioural change, and the outcomes that will result from this. This alignment of views ensures that there is a mutual understanding and collaboration towards

common goals by both parties (Heisler et al., 2003). In a program which targets youth, it is also important to consider the views of parents who have a significant impact on the behaviour of their child, and whose own behaviour also influences that of their child.

This thesis examines the views of patients, parents, and providers at the Centre for Healthy Active Living (CHAL), a clinical obesity management program for children and youth run through the Children's Hospital of Eastern Ontario (CHEO), in Ottawa, Canada. Content analysis, a qualitative methodological approach was used to determine the alignment of views between patients, families, and providers, in relation to the formal goals of the CHAL program. This approach may benefit future programs with behavioural therapy components to determine alignment of views between patients and providers in their program.

2. Literature Review

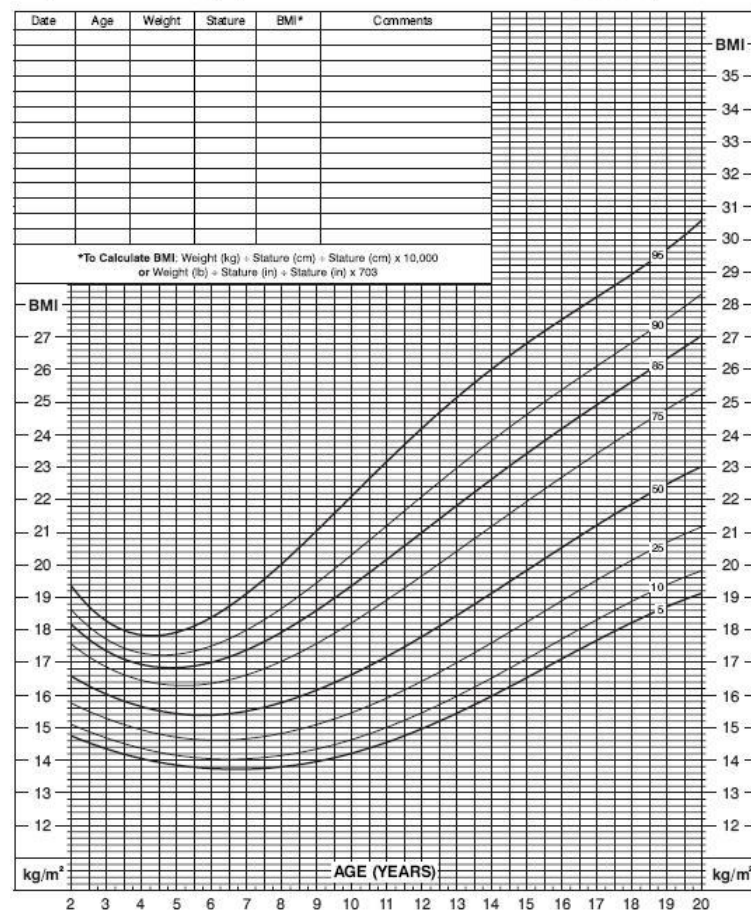
2.1 Clinical obesity

Clinical obesity is a medical condition where there are high levels of fat in the body. “Strictly speaking, overweight refers to weight in excess of a weight standard, and obesity refers to excess body fat. However, because body fat is difficult to measure, body weight is often used as a surrogate measure or indicator of obesity.” (Ogden & Flegal, 2010, p. 1). The diagnosis of obesity generally relies on an individual having a Body Mass Index (BMI) in the 95th percentile for their gender and age. BMI is a ratio indicator of weight and height, where weight in kilograms is divided by height squared in meters (Barlow, 2007). This value does not measure body fat directly, however it is an assessment which is feasible to measure, and is generally taken as the accepted form of obesity diagnosis in a clinical setting (U.S. Centers for Disease Control, 2000). The 95th percentile point was chosen by an expert committee as a stable cut-off point for the diagnosis of obesity. This cut off point was deemed to be one which took a balanced approach between over- and under-diagnosis (Barlow, 2007). BMI is distributed into categories which help to determine overall health and risk level of an individual. Those in the 5th to 85th percentile are considered to be at a healthy weight. Those in the 85th to 94th percentile are considered overweight, and those in the 95th percentile or greater are deemed obese. There is another category which is emerging. Those individuals who are greater than the 99th percentile in terms of their level of body fat compared to the rest of the population for their age and gender are deemed to be in the category of severe obesity. These individuals are in a health crisis, and are at high risk of having immediate health problems (Barlow, 2007).

Although BMI is the most widely accepted tool for diagnosis, it should be used alongside other screening tools such as a health assessment (Barlow, 2007). For example, many body builders who are physically very muscular would technically have a high BMI, so it is important to also consider other factors such as body shape and performance on

physical fitness tests. Also, although BMI is a measurement tool used to assess body fat, body fat is not the only indicator of obesity. Classification of obesity using BMI is not always appropriate in a clinical setting. The Edmonton Obesity Staging System (EOSS) examines staging obesity based on health metabolic, mechanical, mental health, and environmental risk factors (Sharma & Kushner, 2009). The CHAL team in partnership with other experts across Canada are working to adapt the EOSS to a pediatric population (Hadjiyannakis, 2013).

Different age groups have varying BMI distributions. It is especially important that when assessing children for obesity, the child's specific age and gender BMI values are considered as the body composition between children of different ages and genders differs (U.S. Centers for Disease Control, 2000). The BMI-for-age weight charts for boys and girls from the United States Centers for Disease Control are shown in figure 1 and figure 2.

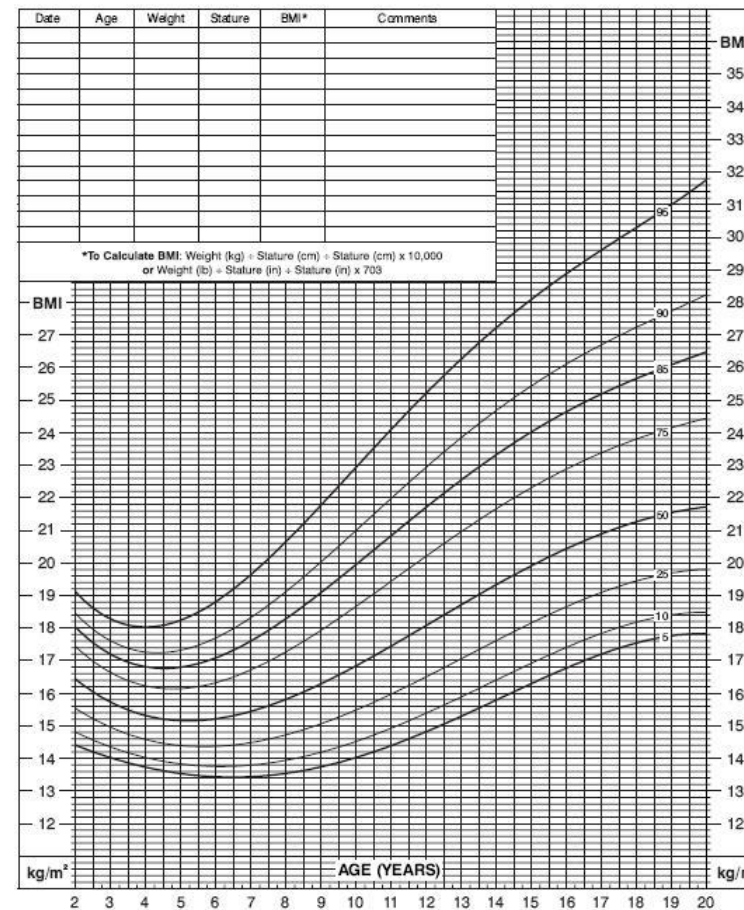
NAME _____
RECORD # _____

SOURCE: Developed by the National Center for Health Statistics in collaboration with the National Center for Chronic Disease Prevention and Health Promotion (2000). <http://www.cdc.gov/growthcharts>



SAFER • HEALTHIER • PEOPLE

2 to 20 years: Girls
Body mass index-for-age percentiles

NAME _____
RECORD # _____

SOURCE: Developed by the National Center for Health Statistics in collaboration with the National Center for Chronic Disease Prevention and Health Promotion (2000). <http://www.cdc.gov/growthcharts>



SAFER • HEALTHIER • PEOPLE

Figure 2. CDC BMI chart for girls (U.S. Centers for Disease Control, 2000).

Although the terms overweight and obese are used in clinical terms to denote a patient's weight status, an expert committee formed in 2005 by collaboration between the American Medical Association and U.S. Centers for Disease Control and Prevention does not recommend clinicians using these terms when speaking with patients or families for risk of seeming judgemental and making the patient feel ill at ease (Barlow, 2007).

2.1.1 Factors contributing to obesity in children

There are a variety of factors which contribute to the increasing prevalence of children who are obese. There are genetic factors which predispose an individual to developing obesity. Mutations in certain genes predispose children to a rare form of obesity called monogenic severe obesity, however common forms of obesity in individuals can also be attributed to some genetic predisposition (Bottcher et al., 2011). Twin studies demonstrate that there are genetic, as well as environmental factors which lead to an increased risk of obesity in children and youth (Barlow, 2007; Bottcher et al., 2011). It is important for health care providers to recognize that there is a genetic component to obesity, and that because certain children are predisposed to this condition, that a proactive approach to obesity management is required for these individuals. There is also a risk factor for children of mothers who were overweight during pregnancy. Children of mothers who were overweight pre-pregnancy and those who had gestational diabetes were at a higher risk of being overweight at sixteen years of age, compared to those whose mothers were at a normal weight pre-pregnancy (Pirkola et al., 2010). Obesity is also associated with certain high risk behaviours, including substance abuse associated with obese girls and a relationship between obese boys and violent behaviour (Farhat, Iannotti, & Simons-Morton, 2010). It is important to note that this topic has not yet been well researched, and does not claim causality, simply association between the two factors.

Lifestyle choices and behaviour play a major role in contributing to a child's health and weight status. Healthy eating habits such as the consumption of more fresh fruits and vegetables versus processed foods are essential in maintaining a healthy diet. Increasingly, youth are relying on processed foods, negatively affecting their health status (McPhail, Chapman, & Beagan, 2011).

An increase in sedentary activity also negatively affects the overall health of youth. The time spent on video games, computers, and television watching is increasing, while the time spent engaging in active behaviour is decreasing for the overall population and for youth in particular (Tremblay et al., 2011). To add to this, youth who are naturally less athletically inclined are even less likely to engage in active behaviours the more they play video games. In video games where they perform well and are successful, they receive rewards. This gives them intrinsic motivation to play more of these video games, and increase their game time even more. Due to this, they further increase their screen time, and decrease the time available for physical activity. Parents, coaches, teachers, and others who play a key role in keeping youth active must recognize this need for intrinsic motivation for the youth, and find a way to foster this intrinsic motivation during physical activity so that the youth will want to spend more time partaking in physical activity, which will ultimately benefit their weight status, and overall health status (Jaballas, Clark-Ott, Clasen, Stolfi, & Urban, 2011). Also, parents setting limits in terms of television watching and screen time was shown to be an effective strategy in decreasing the amount of sedentary activity for youth (Carlson et al., 2010). Effective strategies to motivate youth to participate in physical activity include using the achievement of physical activity targets to allow access to sedentary activities (such as screen time activities), as well integrating physical activity into school curriculums (Lubans, Morgan, & Tudor-Locke, 2009). There is also evidence that lack of sleep contributes to being obese, so it is important that parents enforce proper sleep schedules, especially as their children age (Ball et al., 2008).

Finally, low socio-economic status is also associated with obesity (Bambra, Hillier, Moore, & Summerbell, 2012). As those with a lower socio-economic status generally have poorer access to fresh foods, as well as greater difficulty of access to organized recreational activities such as sports due to high enrolment fees. It is important that a public health approach be investigated at an individual, community, and society level, to target the needs of those with lower socio-economic status (Bambra et al., 2012).

Genetic, biological, environmental, social, and individual factors contribute to the weight status, and overall health of children. It is important to recognize and mitigate these risk factors in order to maintain the health of the young population.

2.1.3 Why obesity is important to control early on

It is important to diagnose and treat obesity early on in children and youth, as obesity is a condition that will persist throughout an individual's lifetime if not adequately treated (Jaballas et al., 2011); this will have a negative impact on the individual's health due to associated co-morbidities, as well as on the individual's quality of life.

The majority of practitioners agree that the best time to intervene with cases of childhood obesity is at an early age, and many professional associations such as the National Association of Pediatric Nurse Practitioners call for interventions in the areas of lifestyle and exercise modification (Jaballas et al., 2011). These behaviour modifications can have a large impact on the disease progression if made early on, as there is greater chance of making significant improvements towards eliminating the condition later in life (Whitaker, Wright, Pepe, Seidel, & Dietz, 1997).

It is also important to treat this condition early on, as children who are obese tend to have an overall lower quality of life compared to those who are not obese. Areas of greatest concern include children who are obese having lower self-esteem, being more likely to suffer from disorders such as anxiety and depression, and showing immature and aggressive behaviour (Friendlander, Larkin, Rosen, Palermo, & Redline, 2003). According to a separate study, along with weight status, children who have higher levels of physical activity, and a better diet also had a higher quality of life (Wu, Ohnima & Veugelers, 2011).

Obesity is linked to a number of co-morbidities which negatively affect the health of children. Individuals who are obese are at an increased risk for a variety of conditions including asthma, coronary artery disease, depression, diminished self-esteem, hypertension, insulin resistance, metabolic syndrome, non-alcoholic fatty liver disease, osteoarthritis, sleep apnea, stroke, and type two diabetes (Adamo et al., 2010; Barlow, 2007; Lau et al., 2007). These co-morbidities often require intensive medical treatment to manage, and negatively impact the long-term health and quality of life for children. Often, the effects of many of these conditions are not reversible (Lau et al., 2007).

Another reason it is important to treat childhood obesity early on is that numerous studies have shown that those who are obese in their childhood and youth tend to remain obese into and throughout adulthood (Barlow, 2007; Jaballas et al., 2011; Janssen, Katzmarzyk, Boyce, King, & Pickett, 2004; Seliske, Pickett, & Janssen, 2012).

Due to the risks associated with obesity on the health and quality of life of children, and the risk of obesity persisting into adulthood, creating a vicious cycle that becomes difficult to break, it is important that clinical obesity management programs for children and youth exist, and that they are effective in treating obesity for this population.

2.2 Clinical obesity management programs

A framework that is being promoted at various levels of government in Canada is outlined in the report *Actions Taken and Future Directions 2011- Curbing Childhood Obesity: A Federal, Provincial and Territorial Framework for Action to Promote Healthy Weights*. This report emphasizes the role that various levels of government are taking to address the childhood obesity epidemic. The framework centers around three main strategies including:

- i. “Making childhood overweight and obesity a collective priority for action”.
- ii. “Coordinating efforts [at all levels of government] on three key policy priorities: Supportive Environments, Early Action, Nutritious Food”.
- iii. Measuring and reporting collective progress.” (Public Health Agency of Canada, 2011).

This framework was developed as a result of the collaboration that was done between stakeholders to help Canadians make healthier choices: a successful pilot project of strategies towards promoting health weight in children and reducing sodium in the diets of Canadians led to an increased commitment in 2011 to identify and work towards new strategies to help Canadians live healthier lives (Public Health Agency of Canada, 2011).

Obesity management programs are one of the intervention strategies that address the most severe cases of childhood obesity in Canada (Public Health Agency of Canada, 2011). Effective and supportive clinical obesity management programs are needed in order to equip families with the knowledge and tools needed to manage the condition of obesity in children and youth. These obesity management programs are different than traditional patient-practitioner relationships, and require a multi-disciplinary team approach that is tailored to the needs of the individual and their family (Barlow, 2007).

The traditional approach of one clinician working with their patient in an office setting works well for acute illnesses, however chronic disease management, such as obesity management, requires an approach that combines education, health care from a multidisciplinary team, and self-management techniques to form the base of the patient's treatment plan (Barlow, 2007). In the case of children and youth, it is important to involve their family in this approach as well, as the family is usually the main source of support and care for the individual who may not yet have the capacity to self-manage their care.

According to McClaskley (2010) "research demonstrates that obesity is a complex and multi-faceted problem requiring multiple approaches and solutions utilizing a team management strategy." Intervention programs which manage obesity have a number of common characteristics. They are generally associated with a clinical institution, have a clear referral process, and involve a care team composed of professionals from a number of clinical and non-clinical disciplines including psychologists, nurses, endocrinologists, child and youth workers, dieticians, and exercise specialists (Children's Hospital of Eastern Ontario Centre for Healthy Active Living, 2011). It is important that these individuals work as a team and are involved in a coordinated approach with the patients care (Barlow, 2007). Clinical obesity management programs should ensure that their mandate and goals are clear to the patients from the beginning of the process, in order to have synergy and alignment between views and goals of the patients, and those of the providers.

Ideally, obesity management programs should be situated close to a child's home in a familiar environment (McClaskley, 2010). One study showed that while rates of obesity are generally higher in suburban areas, this is not necessarily the case for children and youth. Due to a high degree of urban sprawl and lack of other means of transportation, youth in these areas relied on active means of transportation, such as bicycling, to get to their destinations (Seliske et al., 2012). Using information such as this makes a strong case for having obesity management programs close to the youth, as they can encourage active transportation for youth to participate in the program; otherwise they would have to rely

on their parents to transport them to youth sessions of the program. Furthermore, since practitioners are familiar with the neighbourhood, they can talk to youth about active transportation in their community. These clinical obesity management programs should emphasize lifestyle changes instead of relying on medication (Skinner, Mayer, Flower, & Weinberger, 2008).

The healthcare team should be diligent about monitoring patient progress with routine tests and assessments to determine if patients are meeting their goals (Barlow, 2007). It is also important that there is communication of this information with the child's primary physician. One of the main frustrations of primary care physicians when treating obesity is a perceived lack of support and coordination from obesity clinics with respect to their patients (McClaskey, 2010).

2.2.1 Outcome measures

There are four main areas in which outcome measurement takes place for the majority of clinical obesity management programs. These categories include medical measures, behaviour change, patient satisfaction, and overall quality of life. In the case of childhood clinical obesity management programs, most, but not all of the measures include a parent counterpart measure as well.

2.2.1.1 Medical measures

Clinical obesity management programs include a series of assessments done over the span of the patient's participation in the program in order to monitor progress of the

patient's medical profile over the course of the treatment (Children's Hospital of Eastern Ontario Centre for Healthy Active Living, 2011). Typically, these medical assessments are done at specific time intervals: for example, an initial baseline assessment with a follow up assessment completed every six months. An example of medical assessments which are done at the Centre for Healthy Active Living program include glucose homeostasis; OGTT (oral glucose tolerance test); blood lipid profile; liver enzymes & renal function; hormones & adipokines; non-traditional CVD (cardio-vascular disease) risk factors; body composition & neck circumference; waist circumference, height, weight, and BMI; blood pressure; abdominal ultrasound, apnea/hypopnea index; parental height and weight; parental medical & mental health history. Patients also complete a dietetic, physical activity and mental health assessment. Measures are also taken to evaluate these components of health throughout the program (Children's Hospital of Eastern Ontario Centre for Healthy Active Living, 2011). A complete table of these measures is found in table 2, in the CHAL program outline section.

2.2.1.2 Behaviour change

Behaviour change activities focus on those lifestyle habits which may have influence on an individual's weight status. The majority of these behaviour changes are required in the areas of healthy eating and physical activity. Proper nutrition and adequate levels of physical activity can aid an individual to become healthier, and also to maintain their body mass index, and may eventually help to lose weight (Jaballas et al., 2011). Ultimately, the goal for practitioners is to help patients identify these lifestyle behaviours, and give them the tools to succeed in modifying their behaviour to improve their health. It is important that clinicians not only help families identify which behaviours they may want to change, but also to give them the skills on how to do so (Barlow, 2007). For example, families may be trying to encourage their children to participate in physical activity, however may not

have the financial resources for their child to participate in organized sport, so it may be up to the clinician to suggest alternatives to increasing the child's physical activity levels. Also, in childhood obesity programs it is essential to monitor parent lifestyle behaviour as well, and suggest strategies for change in this capacity if needed; this is important as children tend to model the behaviour that they see.

Most behaviour assessments are self-reported by children or by their parents; one limitation of this type of assessment includes measurement validity (Barlow, 2007). According to an expert report by Barlow (2007, p. S166) "these methods are inaccurate and subject to underreporting" when discussing reporting methods for eating habits of participants, such as using a food diary. Barlow goes on to state that "Standardized instruments simplify assessment of usual diet and activity behaviors...None assesses all of the targeted behaviors comprehensively, and none has been tested for reliability and validity in a clinical setting." (Barlow, 2007, p. S181). The authors emphasize the need for more research in this area.

It is also difficult to measure the impact that any such behaviour has on the weight status of a child since many of the detrimental lifestyle behaviours co-exist. The target behaviours that the Expert Committee recommends are as follows:

- 1) "Limiting consumption of sugar-sweetened beverages;
- 2) "Encouraging consumption of diets with recommended quantities of fruits and vegetables;
- 3) "Limiting television and other screen time;
- 4) "Eating breakfast daily;
- 5) "Limiting eating out at restaurants, particularly fast food restaurants;
- 6) "Encouraging family meals in which parents and children eat together;
- 7) "Limiting portion size." (Barlow, 2007, p. S171).

2.2.1.3 Patient satisfaction

Most clinical obesity programs tend to measure both patient and parent satisfaction, at various points of the program. This is very important in terms of patient outcome improvement through other outcome measures, as patients who are more satisfied tend to remain in the program (Cote et al., 2004). It is important for patients to adhere to a program regimen and stay with the program for as long as it is necessary to treat their condition in order to increase their chances of managing their condition (Cote et al., 2004).

Physicians have a great deal of influence over how patients feel about their health care. In general, a physician's recommendations seemed to be most effective for a patient when explained in a positive manner. Practitioners who were personable and reassuring were more effective with their recommendations than those physicians who were more formal and perceived as cold by their patients (Di Blasi, Harkness, Georgiou, & Kleijnen, 2001). In terms of youth obesity programs, parents whose child's physician assessed measures such as parent confidence, concern, and readiness to change reported a higher level of satisfaction with their child's care (Rhee, De Lago, Arscott-Mills, Mehta, & Davis, 2005).

2.2.1.4 Quality of life

The overall goal for all healthcare programs is to improve the quality of life for the patients of the program. Tools are used to measure quality of life, to determine if a program is being effective in this manner. The PedsQL is such a tool which is often used to measure quality of life for children with parents as proxy-respondents; this tool has been shown to accurately represent children through the lens of their parent (Williams, Wake,

Hesketh, Maher, & Waters, 2005) and is the tool used to assess quality of life for the CHAL program's patients.

2.2.2 Alignment of views

In a healthcare context which requires extensive cooperation and participation from both providers as well as their patients, it is important that the views of both parties are understood, and that there is at least general agreement between these two views (Heisler et al., 2003). In a treatment program which includes a behaviour management component, such as is the case with clinical obesity management programs, it is vital that the views of patients are brought forward and understood (Foster, et al., 2005). Often, patients are hesitant to express their ideas, concerns, and health related goals, because practitioners are considered the experts and there is a power imbalance that is still implicit in patient-health care provider interactions, especially when it comes to interactions with physicians (Bylund, Peterson, & Cameron, 2012). Patients may have views which they are hesitant to articulate, or which may be subconscious but that still influence the patients' behaviour. It is important that patients are given the opportunity to share these thoughts in a safe environment and that they are made to feel that their thoughts and opinions are valued. In the case of clinical programs which have child and youth patients, it is also imperative to include the views of parents and families who have a major influence on the children's lives (Crawford, Timperio, Telford, & Salmon, 2005).

“Several studies of obesity treatment in children have demonstrated the importance of parents' participation in weight control programs. The commitment of parents and other caregivers to helping the child develop healthy habits to prevent obesity is likely to be very important. Parents can serve as role models, authority figures, and behavioralists to mold their children's eating and activity habits. Clinicians can influence children's habits indirectly

by teaching and motivating parents to use their authority effectively. For very young children, clinicians should focus the discussion on parenting behavior. The greater independence of adolescents means that clinicians should discuss health behaviors directly with them, although clinicians should encourage parents to make the home environment as healthy as possible.” (Barlow, 2007, p. S172).

The views of providers also play a major role in influencing the treatment of their patients. Although in the case of clinical treatment programs, such as clinical obesity management programs, providers generally work as representatives of a certain organization and operate within that organization’s mandate, they often have their own views and biases based on their training, experience, and personal views. Whether these are expressed implicitly or explicitly, these views affect the treatment of their patients in some way.

The alignment of views between patients and providers is important to achieving a greater chance of success for the patient treatment plan. One way of achieving this is for the program to adopt outcome goals through consultation with both patients and providers; it is important that a collaborative approach is taken so that there is understanding of goals from both sides (Uhlenhake, Kurkowski, & Feldman, 2010). Also, clinicians may be able to tailor their recommendations in a way which assists patients in reaching these goals. “[A] clinician's knowledge of an individual family's personal values and circumstances, which are not dictated by the family's ethnic, racial, or economic group, may be most helpful in tailoring recommendations.” (Barlow, 2007, p. S171).

Ultimately, success of a patient’s experience in a program largely depends on the expectations and views of that patient, and how closely these are aligned with the provider expectations, and if established, formal program goals.

2.2.3 Evaluation Frameworks

Current evaluation frameworks of clinical obesity management programs constitute a spectrum of approaches. On one hand, evaluation components focus on clinical outcomes measures, and efficiency measures such as patients outcomes and cost analysis (Bambra et al., 2012; Cote et al., 2004; Dhorajiwala, Thornton, Bose-Haider, & Puttha, 2010; and Kuhle, Kirk, Ohinmaa, & Veugelers, 2011). These quantitative measures focus on proving the effectiveness of programs with regards to their measurement of targets. On the other hand, other evaluation frameworks focus on the experience of the patient, or the parents in terms of their satisfaction towards the program (Adamo et al., 2010; Eckstein et al., 2006; Jaballas et al., 2011; and Rhee et al., 2005). Figure 3 shows the spectrum of evaluation frameworks.

Clinical outcome and efficiency	<i>Health care utilization from prevalent medical conditions in normal-weight, overweight, and obese children. (Kirk et al., 2012).</i> <i>Tackling inequalities in obesity: a protocol for a systematic review of the effectiveness of public health interventions at reducing socioeconomic inequalities in obesity amongst children. (Bambra et al., 2012).</i> <i>Service quality and attrition: an examination of a pediatric obesity program. (Cote et al., 2004).</i> <i>Scopes, limitations and satisfaction in managing childhood obesity in primary and secondary healthcare services' time for improvements. (Dhorajiwala et al., 2010).</i> <i>Using path analysis to understand parents' perceptions of their children's weight, physical activity and eating habits in the Champlain region of Ontario. (Adamo et al., 2010).</i> <i>Factors associated with parental readiness to make changes for overweight children. (Rhee et al., 2005).</i>
Patient satisfaction	<i>Parents' perceptions of their child's weight and health. (Eckstein et al., 2006).</i>

Figure 3. Spectrum of clinical obesity evaluation frameworks.

There have been studies done in other areas of health care which focus on the alignment of views between patients and providers. Heisler et al. (2003) focused on patient-provider collaboration in the area of diabetes management. They found that in general, there was poor alignment with diabetes management practices between the two groups. They also found that “agreement was associated with higher patient self-efficacy and assessments of their diabetes management... enhancing patient-provider agreement on both overall treatment goals and specific strategies to meet these goals may lead to improved patient outcomes.” (Heisler et al., 2003, p. 893).

A study by Uhlenhake et al. (2010) focused on the patient-physician relationship and expectations when discussing the treatment of psoriasis. The study found that there were discrepancies between expectations of both parties and treatment may be enhanced by sharing these treatment expectations up front.

Richman (2007) states that “Pursuing goals without patient buy-in is not just likely to fail, but is generally speaking, contrary to the physician’s duty to respect patients as persons.” (p. 451), emphasising the idea of patient-centered care. The same duty can be applied to all health care professionals. It is important to consider the expectations of patients with relation to goals of the program in order to respect the patient’s autonomy and role in their care.

3. CHAL Program

3.1 Introduction to the program

The Centre for Healthy Active Living (CHAL) is an outpatient program for children and youth with complex, severe obesity. The program is run through the Children's Hospital of Eastern Ontario (CHEO), in Ottawa, Canada. The CHAL program is designed to treat obesity and related co-morbidities in children and youth up to seventeen years of age.

The mission of the Centre for Healthy Active Living at CHEO is: "To provide a comprehensive, coordinated, family-based treatment approach for children and youth with complex severe obesity requiring sub-specialized medical care." (Children's Hospital of Eastern Ontario, 2012). The members of the CHAL team strive to fulfill this mandate by gearing participants towards the attainment of the program's goals.

The focus of the program centers on the Realistic Eating Active Living (REAL) strategy. The REAL program is an interdisciplinary, family centered approach to care, which combines group based psycho-education with motivational and supportive counselling. The program focuses on the strengths of the patients and their families. (Children's Hospital of Eastern Ontario, 2012).

The REAL program has seven goals which patients and their families strive towards:

- 1) "Improve quality of life.
- 2) "Decrease medical and psychological co-morbidities.
- 3) "Improve eating behaviours.
- 4) "Improve fitness, increase activity levels.
- 5) "Decrease sedentary behaviour.
- 6) "Empower/strengthen families.

7) “Stabilize BMI trajectory.”

These goals emphasize the importance of a multidisciplinary, family centered approach to care (Children’s Hospital of Eastern Ontario, 2012).

To be eligible for the program, a patient must meet inclusion criteria and be referred by their physician. These criteria include:

- Age up to and including 17 years.
- Body Mass Index (BMI)
 - In the 99th percentile *or*
 - In the 95th percentile and associated with a severe co-morbidity or chronic illness.

These co-morbidities include hypertension or hyperlipidemia requiring pharmacotherapy, sleep disordered breathing that is technology dependent, persistent impaired glucose tolerance or impaired fasting glucose, type two diabetes, polycystic ovarian syndrome, non-alcoholic fatty liver disease, hypothalamic obesity, and any chronic disease that is negatively impacted by obesity (Children’s Hospital of Eastern Ontario, 2012).

Health issue	Percent of population affected (%)
Hyperlipidemia	51
Learning disorder	31
Asthma	30
Non-alcoholic fatty liver disease	22
Polycystic ovary syndrome	17
Anxiety	15
Sleep apnea	15
Depression	14
Gastro-esophageal reflux	14
Hypertension	8

Table 1. Health issues affecting the CHAL patient population (Children’s Hospital of Eastern Ontario, 2012).

3.2 Program participation

The CHAL program includes an information session for parents to be introduced to the program, an assessment component which includes monitoring of several measures at different points of time, and an active treatment phase which the patients and their parents have the option of starting at any time after their enrolment in the program. Figure 4 shows the different components of the program.

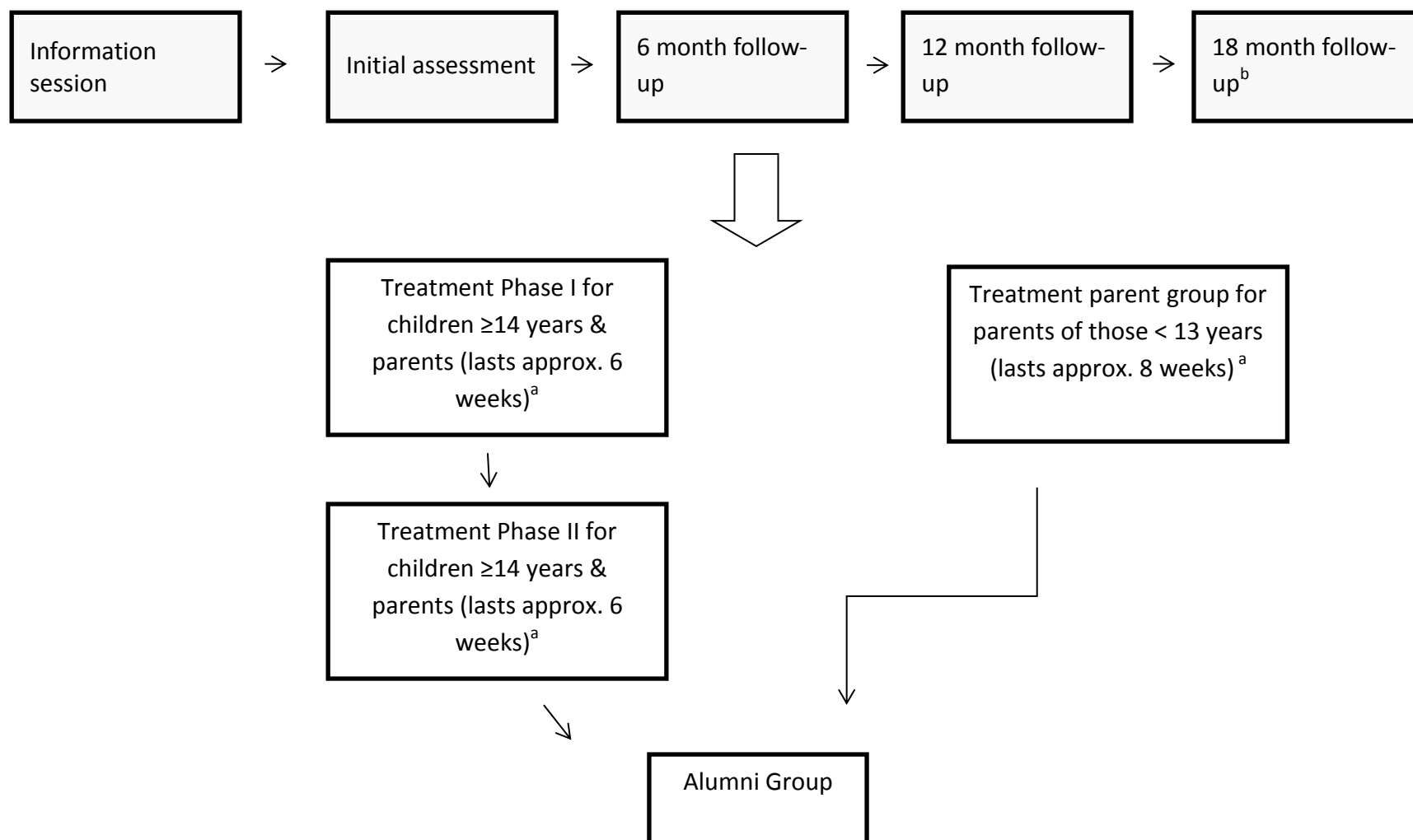


Figure 4. Patient Flow Diagram. The initial assessment and follow up appointments are scheduled for every patient who consents to participate in the CHAL program. The treatment phase can begin at any point after the initial assessment (not necessarily before the follow up appointments occur).

^a REAL Program Feedback Forms administered (completed by children ≥ 12 years & parents) (Appendix B).

^b Follow-up assessments are conducted every 6 months until the youth reaches 18 years.

3.2.1 Information session

Parents are referred to the CHAL program by the primary care physician of their child. The child's physician makes the referral to the CHAL program based on the program's criteria of age, as well as BMI and/or co-morbidity (see section 3.1.3). The information session is a chance for parents to hear about the CHAL program's philosophy, mission, and goals. The CHAL team presents the treatment outline of the program, and explains the commitment that is required from participants who choose to enter the program. The initial information session allows potential patients and their families to be exposed to the program, meet some of the program staff, and make an informed decision regarding whether or not to participate in the program. This decision may involve many factors including deciding whether CHAL's philosophy towards managing the condition of childhood obesity matches that of the parents and children, and also whether the family is prepared to make the commitment that is being asked from the program. It is important that once the family decides to participate in the program, they are able to maintain this commitment to ensure that the program is effective. Also, there is a waiting list for some phases of the program, so it is important that families do not take up spaces from other candidates if they are not fully committed. The initial information session is also the first time that the families are exposed to CHAL's goals. This initial exposure gives families a chance to determine whether these goals of the program may be complementary to their own goals of managing their child's condition.

At the end of the information session, families have three potential options which they may choose:

- i. Enrol in the program, and participate in the active treatment phases.
- ii. Enrol in the program, but without participation in the treatment phases.
- iii. Do not enrol in the program.

The decisions made by families as to which option to choose takes into account a variety of factors. Families may not live near the Centre, and may find it challenging to commit to attending the treatment phases, however may still wish to remain connected to the program. Some participants may not agree with the philosophy or goals of the program, and therefore may choose not to participate in the program in any capacity.

3.2.2 Patient assessment

Patient assessments are a time for the patients to meet with the different practitioners on the CHAL team who perform a series of assessments with the patients and their families. An initial assessment is completed when the patient enters the program, with a follow up assessment completed every six months. At the patient's initial assessment, baseline data is gathered to establish a measure for any future data to be compared with. This allows practitioners to determine if any progress is being made in a variety of areas. The initial assessment includes measures taken in a variety of areas including Body Mass Index, Readiness to Change, and lifestyle related questionnaire to name a few. Table 2 illustrates outcome measures taken at each point in the program.

CHAL Outcome Measures

Medical Measures		Asmt	6 mos	12 mos	18 mos	24 mos	Pre Ψed	Post Ψed	Pre-Int	Post-Int
Glucose homeostasis (<i>fasting: glucose, insulin</i>)		X	X	X	X	X				
OGTT		X		X		X				
Blood Lipid Profile (<i>fasting: total chol, LDL, HDL, triglyc</i>)		X	X	X	X	X				
Liver enzymes (<i>ALT, AST</i>) & Renal function (<i>urine/alb/creatinine ratio</i>)		X	X	X	X	X				
Hormones (<i>females only</i>) & Adipokines (<i>adiponectin, leptin</i>) + apo-B		X		X		X				
Non-traditional CVD risk factors (<i>extra blood draw</i>)		X		X		X				
Body Composition + Neck Circumference		X		X		X				
Waist Circumference, Height, Weight, and BMI		X	X	X	X	X			X	X
Blood Pressure		X	X	X	X	X				
Abdominal Ultrasound		X								
Apnea/hypopnea Index		X		X		X				
Parent Height and Weight		X	X	X	X	X				
Parental Medical & Mental Health History		X								
Psychological Measures		Asmt	6 mos	12 mos	18 mos	24 mos	Pre Ψed	Post Ψed	Pre-Int	Post-Int
Youth	Children's Depression Inventory	X	X	X	X	X			X	X
	Multidimensional Anxiety Scale for Children	X		X		X			X	X
	Pediatric Quality of Life Inventory - <i>child/teen</i>	X	X	X	X	X	X	X	X	X
	Eating Disorder Examination Questionnaire ¹	X		X		X			X	X
	Body Esteem Scale for Adolescents and Adults ²	X	X	X	X	X			X	X
	Rosenberg Self-Esteem Scale	X		X		X			X	X
	Readiness to Change	X	X	X	X	X	X	X	X	X
	Family Assessment Measure	X	X	X	X	X			X	X
	Best Health Questionnaire	X		X		X	X	X	X	X
	Pacific-Rim Bullying Measure	X	X	X	X	X				
	Impact of Weight on Quality of Life – Kids ³	X	X	X	X	X	X	X	X	X
	Dutch Eating Behaviour Questionnaire ⁴	X	X	X	X	X			X	X
	Sentence Completion	X								
	Canadian Occupational Performance Measure								X	X
	Client Satisfaction Questionnaire	X ⁴						X		X
Parents	CHAL (<i>Parent intake /demographics</i>)	X	X	X	X	X				
	Children's Behaviour Checklist	X		X		X				
	Readiness to Change	X	X	X	X	X	X	X	X	X
	Family Assessment Measure	X	X	X	X	X			X	X
	Parental Eating Attitudes Questionnaire	X		X		X				
	Attitudes and Patterns of Eating	X		X		X			X	X
	Best Health Questionnaire	X		X		X	X	X	X	X
	Impact of Weight on Quality of Life- <i>parent report</i> ⁵	X	X	X	X	X				
	Pediatric Quality of Life Inventory - <i>parent report</i>	X	X	X	X	X	X	X	X	X
	Pediatric Quality of Life Inventory- <i>healthcare satisfaction</i>	X ⁶	X	X	X	X		X		X
Client Satisfaction Questionnaire								X		X
Fitness & Dietetic Measures		Asmt	6 mos	12 mos	18 mos	24 mos	Pre Ψed	Post Ψed	Pre-Int	Post-Int
Youth	Physical Activity Questionnaire - <i>child</i>	X		X		X			X	X
	Habitual Activity Estimation Scale - <i>adolescent</i>	X	X	X	X	X			X	X
	Sedentary Activity Questionnaire	X	X	X	X	X			X	X
	Aerobic Fitness (<i>VO₂max</i>)	X	X	X	X	X				
	Physical Activity Recall	X	X	X	X	X				
	Accelerometer	X		X		X				
	Food & Beverage Habits	X		X		X				
Parents	Physical Activity Questionnaire - <i>parent report</i>	X	X	X	X	X				
	Child Feeding Questionnaire	X		X		X				

☒ = CHAL + Cathexis ☐ = CHAL

17.Mar.2011

Table 2. CHAL outcome measures taken at each time point. (Children's Hospital of Eastern Ontario Centre for Healthy Active Living, 2011).

Following the initial patient assessment, patients and their families have the option of beginning the active treatment part of the program. The CHAL treatment plan is broken down into two separate groups. For children who are less than twelve years of age, their parents participate in the group behavioural therapy, and there is no active participation in the group component by the children. For children aged twelve to seventeen years, the treatment plan includes separate group sessions for the youth and their parents. Patients and families may also ask for individual consultation from members of the CHAL team. Each treatment phase is described below.

3.2.3 Active treatment

The Realistic Eating and Active Living (REAL) program is the active treatment program which helps families gain the skills to address their child's condition of clinical obesity. In the first phase of the REAL treatment program, parents and youth have the opportunity to become familiar working in a group setting. The main focus of this phase is to provide education to the youth and their families about healthy lifestyle behaviours for the whole family. (Children's Hospital of Eastern Ontario, 2012). The second phase of the program is for youth and families who have already completed Phase I. Phase II builds on the knowledge acquired by participants in the previous phase and focuses on skill building with an opportunity for participants to set goals. (Children's Hospital of Eastern Ontario, 2012). The alumni group helps participants who have completed the first two phases of the program maintain the skills that they have gained while participating in the active treatment phases. It also allows participants to maintain their network of support in relation to their developed healthy lifestyle behaviours.

Parents of those children under fourteen years of age participate in group intervention without their children present. This group intervention helps parents to

develop strategies on how to deal with different aspects of their families lives which may negatively contribute to their child's weight status. Parents are given the opportunity to learn about nutrition, physical activity, weight science, goal setting, communication and parenting strategies, and behaviour change (Children's Hospital of Eastern Ontario, 2012). Parent group incorporates many similar educational strategies that are given to parents in the parent section of Phase I and Phase II of the treatment program.

4. Research statement and questions

This thesis examines the views of patients, their families, and providers of the Centre for Healthy Active Living at the Children's Hospital of Eastern Ontario, in Ottawa, Canada. The questions addressed in this research include:

- 1) What are the patient and parent perceptions of the CHAL program for children with severe obesity in relation to the CHAL program goals?
- 2) What are the provider perceptions of patient and parent expectations, and goals of the CHAL program?
- 3) Is there alignment between the participant expectations, the provider perceptions of these expectations, and the formal goals of the CHAL program?

5. Methodology

A qualitative research approach was undertaken to explore the research questions. This case study was conducted by studying the Centre for Healthy Eating and Active Living at the Children's Hospital of Eastern Ontario, in Ottawa, Canada.

5.1 Literature review

"[O]ne of the most important reasons researchers turn to previous studies and relevant literature about a topic to be studied is to identify relevant concepts and their definitions." (Berg, 2001, p. 16).

A review of the literature pertaining to the research topic was conducted at the beginning of the study in order to "examine how others have already thought about and researched the topic." (Berg, 2001, p. 19). This was conducted in order to gain an in-depth understanding of the current situation of clinical obesity in youth and to examine an overview of current clinical obesity management programs.

To begin this literature review, a search using PubMed was conducted using the terms "clinical obesity" and "children" in order to find the current scholarly works on these topics. Next, the reference librarian was consulted in order to search journal databases. Concurrently, theory on methodological principles was sought, including works by Miles & Huberman (1994) and Berg (2001) in order to develop a methodology in which to conduct this research. Also, a study was identified which had a similar research question posed, but on a different topic (psoriasis), and which used a similar methodology (Uhlenhake, 2010).

Once the key pieces of literature were identified, and the methodology framework researched, the references of key and recent articles were consulted to locate additional literature until no new concepts emerged from the literature.

5.2 Qualitative Methodology

Qualitative methods are used to examine the views of individuals when the details and reasoning behind these views is the purpose of study for a researcher. Qualitative methodology provides a “greater depth of understanding” (Berg, 2001, p. 2) to the topic being studied. As such this is the ideal methodology to be used when examining the views of a group of individuals in order to gain an understanding of the reasoning behind their views. “Another feature of qualitative data is their richness and holism, with strong potential for revealing complexity; such data provide ‘thick descriptions’ that are vivid, nested in real context, and have a ring of truth that has strong impact on the reader” (Miles & Huberman, 1994, p. 10). In the case of this study, content analysis was used to analyze the views of the respondents through the data obtained, and is further explained in greater detail in the following sections.

5.3 Ethics

The Children’s Hospital of Eastern Ontario Research Ethics Board and the University of Ottawa Research Ethics Board have approved this research (Appendix A). Patients and families participating in the CHAL program had given their consent for responses of feedback forms to be analyzed. The secondary data analysis was authorized by the CHEO Research Ethics Board, and participant information responses were de-identified and

represented by CHAL participant number before the material was given to the researcher. Participants of the focus group have given their consent using the attached Participant Consent Form (Appendix C). This consent form was reviewed with all participants prior to the focus group commencing, and there was agreement and signed consent from all participants to have the focus group audio recorded; all members of the CHAL team gave their consent to participate in the study.

5.4 Data

The data used for this study was gathered through two methods; patient and family data was gathered from questionnaires and provider data was gathered from a focus group conducted with staff of the CHAL program.

5.4.1 Questionnaires

Participant questionnaires were used to collect data to answer the first research question. The participant data to be analyzed is part of the regular data collection process at CHAL. Directly after the last session of an active treatment phase of the REAL program, a questionnaire is given to all participants of the session by the CHAL staff members to lead the session. Youth, mothers, and fathers separately fill out the paper questionnaires on their own. This questionnaire collects information on what the participants found most useful in the program, any suggestions they may have about the program, information regarding logistics of the program, and any general comments that participants would like to share with staff members of the program. Once completed, staff members gather all of the questionnaires. A sample of this questionnaire is included in Appendix B.

All participants of the treatment groups are required to fill out the questionnaire at the end of the active treatment phase in which they are participating, directly after the last meeting in that phase. Inclusion criteria for the questionnaire included those which were completed in English, and those which were completed by a youth (14-17 years), or a mother or father who had a child in the program. Questionnaires completed in French or by a guardian who was not a mother or father were not included in the data to be analyzed. Nearly every questionnaire completed by a participant of an active treatment phase of the CHAL program was included for analysis, based on the aforementioned criteria. Questionnaires made accessible to the researcher had all identifying information removed and were labelled with the patient number (CHAL000X), or corresponding code for the relationship if applicable (CHAL000XM- mother, CHAL000XF- father). Table 3 shows the number of REAL Program Feedback Forms used for analysis from each phase of treatment.

Data Collection Point	Respondent	Number of Respondents
Phase I post	Youth	11
	Mother	10
	Father	8
Phase II post	Youth	8
	Mother	8
	Father	4

Table 3. Number of REAL program feedback forms used for analysis.

5.4.2 Focus Group

A focus group, facilitated in English, was conducted by the researcher with all of the members of the CHAL team for the purpose of this research, specifically to examine the second research question. This focus group comprised of all of the members of the CHAL team, including roles which consisted of a variety of backgrounds: Endocrinologist, clinical

psychologist, registered dietician, exercise specialist, nurse, case manager, child & youth counsellor, administrative assistant, and research coordinator. The entire population of providers of the CHAL program was present for the focus group. The focus group was an opportunity for the CHAL staff to discuss their various roles, their perceptions of the goals of the program, and their views on what the patients believe are the goals of the program. This group was conducted at the beginning of a regular CHAL team meeting. The focus group guide is included in Appendix D.

5.5 Analysis

The REAL Program Feedback Form (Appendix B) patient and family questionnaires were transcribed from the handwritten answers to a Microsoft Office Word Document for ease of analysis. The transcribed data was separated by youth, mother, and father as well as post-Phase I responses, and post-Phase II responses. The focus group recording was transcribed verbatim from the audio recording taken during the focus group.

Content analysis is a research method that is recently being widely used in health studies (Hsieh & Shannon, 2005). "Research using qualitative content analysis focuses on the characteristics of language as communication with attention to the content or contextual meaning of the text." (Hsieh & Shannon, 2005, p. 1278). Data obtained for content analysis can come from a variety of forms, including interviews, focus groups, observations, questionnaires, and various printed resources. Content analysis determines the meaning behind large quantities of words in order to sort it into categories that mean similar things. "Qualitative content analysis is defined as a research method for the subjective interpretation of the content of text data through the systematic classification process of coding and identifying themes or patterns." (Hsieh & Shannon, 2005, p. 1278). Conventional content analysis was used in analyzing the data from the two sources, as the

coding schemes were developed upon looking at the text, without using any guidelines or preconceived notions with regards to the codes used (Hsieh & Shannon, 2005).

The first level of analysis included content analysis, a process in which “[a]n objective coding scheme [is]... applied to the notes or data.” (Berg, 2001, p. 238). Content analysis allows for the data to be streamlined and organized in a way that is can be compared systematically. This was done first by data reduction, where “data reduction refers to the process of selecting, focusing, simplifying, abstracting, and transforming the data that appear in written-up field notes or transcriptions” (Miles & Huberman, 1994, p. 10). These reduced data phrases were assigned themes that were also used to code transcription of the provider focus group data as well. These themes included: goals; weight, shared experiences; knowledge; co-morbidities; holistic; physical activity; healthy food; and family

A second researcher (a co-supervisor) also coded the reduced data independently, and any discrepancies between the themes were discussed. The themes were then mapped to the formal goals of the program, by creating a bank of synonyms and agreed upon terms for each formal program goal. This allowed themes emerging from the patient and provider data to be analyzed in terms of the formal program goals. This was done independently by both researchers and again any discrepancies in the meaning of the formal goals were discussed by the two researchers. This use of multiple investigators ensured rigour and helped to reduce biases that are caused when data is only processed by one researcher (Berg, 2001). Table 4 illustrates the mapping of terms agreed upon by the researchers.

Formal Program Goals	Mapping Description	Themes
Improve quality of life	People, relationships, health	Family involvement
Decrease medical and psychological co-morbidities	Disease, illness, morbidity	Shared experiences of participants; associated co-morbidities of youth; holistic, multi-disciplinary approach
Improve eating behaviours	Eating, nutrition, food, diet, behaviour	Goals of participants; Healthy food knowledge and skills
Improve fitness, increase activity levels	Active living, physical activity, fitness, behaviour, motivation	Goals of participants; Physical activity knowledge and skills
Decrease sedentary behaviour	Physical activity, fitness	Physical activity knowledge and skills
Empower/strengthen families	Relationships, family	Shared experiences of participants; family involvement
Stabilize BMI trajectory	Weight, outcome, obesity	Goals of participants; Weight status of youth

Table 4. Coding grid created by mapping descriptions of formal goals to themes.

6. Results

6.1 Analysis of themes from data

The analysis of the themes from the content of the youth and parent questionnaires, as well as the focus group with the providers, compared to the formal goals of the CHAL program are described below. There were nine main themes that emerged from the analysis of the data: goals of participants; weight status of youth; shared experiences of participants; knowledge acquired by participants; associated co-morbidities of youth; holistic, multi-disciplinary approach; physical activity knowledge and skills; healthy food knowledge and skills; and family involvement. These themes showed important concepts that were brought up by one or more groups during the course of gathering information from the participants. These concepts are presented in table 5 and elaborated on in the sections which follow.

Themes	Youth views	Mother views	Father views	Practitioner views
Goals of participants	Become healthier; Increase confidence	Long-term health goals for children; Behaviour change; Accepting their body; Dressing for their weight; Obstacles identified, solutions less so; Frustration when completed goals not acknowledged by practitioners; Suggestion of parents emailing with weekly progress	Satisfaction towards child receiving encouragement towards their goals; Emphasis on realistic goals; Stress that CHAL not a weight loss program; children should express goals independently of their parents	Focus on the goal setting aspect of the program; Not a weight loss program; Changes in health behaviour; Whole family approach to behaviour change; Youth and family goals may be incongruent
Weight status of youth	Positive views regarding CHAL not being a weight loss program; Wanted to know how to lose weight	Knowledge of nutrition, weight, body image, dieting; Discuss with other parents how to deal with weight; Hope their children would accept their body image; Message of healthy at any weight is wrong	Emphasize this is not a weight loss program	Frustration that many families initially believe CHAL is a weight loss program; Some parents too focused on weight
Shared experiences of participants	Comfort in knowing they are not the only ones; Enjoyed relating to others; No judgement perceived	Sharing and involvement with other families was crucial; Huge sense of support; Sometimes too much emphasis placed on sharing; Some children immature	Importance of their child hearing about behaviour change from someone else; Comforting knowing they are not alone	Group based; Social part of the program important
Knowledge acquired by participants	Understanding on how to manage the condition of obesity; Material presented in a way that was easy to understand; Proud of the knowledge they acquired and wanted to pass it on	Knowledge of communication skills; Appreciation of topics covered; Too much basic knowledge at times, large part of it is review	Right amount of information presented; Enjoyed the medical explanations; Would have like more interactive activities	Phase one is mostly about disseminating information regarding health behaviours and psycho-education

Associated co-morbidities of youth	-	All aspects of obesity covered during the program	-	Associated co-morbidities including physical and mental health issues are addressed during the program
Holistic, multi-disciplinary approach	-	Changing negative thoughts to positive; Appreciated immediate intervention when there was an issue	-	Healthier physically and mentally with an improved quality of life
Physical activity knowledge and skills	Enjoyed physical activity; Wanted more physical activity sessions; Sessions done together relieved excess energy	Wanted more specific knowledge on this topic; Strategies on incorporating different types of physical activity; Interest for organized opportunities in sport; Obstacles identified, solutions less so	Observed changes in their children in terms of physical activity; Wanted a continuum of physical activities	Behaviour participants had control over; Important to encourage this in a positive manner
Healthy food knowledge and skills	Healthy body at any size; Tips on portion sizes; Desire to learn more about food and recipes	Received information on this topic; Appreciated advice regarding a hands-off approach; Wanted more information on meal planning	Seeing positive behaviour changes in their children regarding eating habits; Enjoyed discussions on food; Expressed gratitude about snacks	Presenting nutrition information; Focus on weight maintenance
Family involvement	More family involvement; more opportunities for parents and children to collaborate; Desire to have siblings involved	Desire for siblings to be involved; more time with youth in group sessions; Felt should be told what their children are doing in youth group sessions	Enjoyed open discussions about family dynamics	Importance of having parents actively involved; desire for more fathers to be involved

Table 5. Results from patient/family questionnaires and provider focus groups, by theme.

6.1.1 Goals

All participants identified goals that were important for them or for a participant of the CHAL program to achieve. Youth participants expressed that the program influenced their motivation to become healthier, and implied that the goal of overall better health behaviour came from their participation in the program. Youth also identified that participating in the program helped them to increase their confidence.

Mothers expressed the importance of the CHAL program in helping to identify long-term health goals for their children, and the value that they found in this exercise. One mother expressed “I wish there had been a group like this when I was young- very important message about long term health goals.” Mothers also expressed the desire for behaviour change in their children. Similarly to youth, mothers wanted their children to have an overall healthier set of behaviours. “I am hoping to see some change [in] my daughter[’s] behaviour. Sleep early, eat healthy.” Mothers also expressed the desire for their children to have the goal of accepting their body and dressing appropriately for their weight.

Mothers expressed some goals of theirs which were not met to their satisfaction by the program. Mothers expressed frustration when they felt their child had already completed a behaviour that the practitioner was focusing on. “He [patient/son] also found a lot of time was spent on body image. Since he has a positive body image he found this boring and unnecessary.” Also expressed by a mother was the sentiment that “obstacles were really well identified but solutions less so.” A mother suggested having parents email program staff with weekly progress updates on their goals, and on the goals of their children.

Fathers expressed satisfaction towards their children receiving encouragement towards their goals throughout their participation in the CHAL program. Fathers also

expressed that the program has an emphasis on realistic goals throughout the overall REAL approach. Fathers also believed that expressing the goals of the program should happen explicitly by the practitioners: “Express the fact that this is not a ‘Weight Loss Program’ so that families that believe this statement will not take a spot from a deserving candidate.” Another wish expressed by fathers was the desire to have children in the program come up with their own ideas and goals, independently of their parents. This may be important in terms of behaviour change for youth, as youth may be more inclined to work and strive towards goals which they take ownership over.

Practitioners expressed a strong tendency towards focusing on the goal setting aspect of the CHAL program. Practitioners expressed the need for the program not to be seen by patients and their families as a weight loss program, and believed that this is where some mismatch occurred between family and practitioner goals. Practitioners also emphasized that the changes in health behaviour should be the goals of the families in participating in the program. “those are goals that we set or that changes in health behaviours because that’s... about the only thing you have control over... any change in a health behaviour whether it’s physical activity related, food related, or if it’s mental health related, any changes they make in that, that’s what we’re focusing on and that’s where measure of success we would look for it to be.”

The practitioners emphasized as well that the whole family needs to work together towards the behaviour change goals of the program, and not simply the patients of the program. Another goal for the practitioners was to have patients and families work towards accepting the group therapy and group based treatment and intervention. This is one of the main goals of Phase I of the treatment plan, according to practitioners.

Practitioners also believed that many parents are reluctant to set goals for themselves because they believe that it should be their children who are setting goals and changing behaviours, and not themselves. This again emphasizes the entire family

approach, where the behaviour and lifestyle habits of the whole family are targeted, and not simply those of the youth who experience the condition of obesity. “Children live what they see, not what they hear so the whole family [would] have to change, not just target one individual in the family.” This sentiment did not come across by parent feedback, however the possibility exists that parents felt this way at the beginning of the active treatment phases and during the program learned the importance of family involvement in the goal setting process.

Providers also expressed concern regarding the differences between youth and family goals in the program. “Sometimes the youth and parent goals are a little incongruent because the youth are kind of focused on smaller things and things that they need to achieve right away, like they may be goals focused on school or focused directly on social situations where they can kind of make change, whereas parents are diving into, let’s change their healthy behaviours, let’s change their weight behaviours, so they get a little incongruent with that but generally by the end they’re kind of going in some kind of parallel line.” Providers expressed that they guide parents and families to making their own goals based on the initial assessment day.

6.1.2 Weight

Weight was a theme of central focus for both youth and their parents who are enrolled in CHAL’s program for severe obesity treatment.

Youth expressed positive ideas surrounding the practitioners’ perspective of weight management, with relation to the condition of obesity from which they suffered. Youth expressed “They told us that diets don’t work and that you don’t have to be skinny to be healthy.” “They made sure to always let us know at any size you could be healthy.” This

emphasized the idea expressed that the program is not a weight loss program. However, some youth still wanted knowledge and strategies on how to lose weight.

This perspective was emphasized by both mothers and fathers who had a child enrolled in the program. Mothers expressed that they appreciated the knowledge and discussion surrounding topics of nutrition, weight, body image and dieting. They appreciated the opportunity to discuss with other parents how to help their children deal with their weight. Mothers also expressed hope that their children would accept their body and weight. “I am happy to see some change in my daughter’s behaviour... Accept her body/dress for her weight.” Mothers also appreciated “the discussion on the physical ramifications of being overweight.” Some mothers were not happy with the emphasis put on being healthy at any size, and believed that this was wrong; they did not appreciate this sentiment passed on to their children.

Fathers echoed the sentiment that they learned this was not a weight loss program, and the need to emphasize this. “To reinforce the concepts- key messages should be repeated maybe a flash card? ‘Weight is an outcome- not a goal’”.

It is clear from the feedback received at the end of the treatment phase that youth and parents were in agreement that weight loss was not a main outcome goal of the program.

Practitioners relayed frustration that many families initially had the misconception that the program was designed to emphasize weight loss. “People look at us as a weight management program. There’s a feeling that this also means it’s a weight loss program. Trying to explain our approach is to help them achieve a good [health] and that may not mean that they’ll lose a significant amount of weight in our program, but that hopefully by the end of the program they’ll be healthier both mentally and physically, with an improved quality of life. They need to be okay with that, and I think that, coming [into the] program

some of our patients are really hoping to come in and lose a significant amount of weight.” Some practitioners stated that patients come to them thinking they are a weight loss program, after being referred to the program by their primary health care provider. “I’ve heard some families say that they were referred for weight loss, like they were referred to CHEO to the weight loss program.” This misconception influences the families’ thinking before they even enter the program.

Practitioners expressed disappointment that at the initial information session, when told that CHAL is not a weight loss program, potential patients ask if they should simply go somewhere else for that service. Some parents, according to practitioners, still have the misconception going into the program that they simply want to drop their children off for treatment and have them come back weighing less. Practitioners also expressed concern that some parents were simply too focused on weight loss for their child and did not see the whole picture. “They’re so focused on the weight loss they miss out on the successes their family has achieved because they’re just focused on measuring success based on the number on the scale.” Members of the CHAL team also wanted to educate the parents on the concepts of “weight loss” versus “weight management” when the latter is the whole lifestyle approach. They emphasized that there is no magic solution to weight management, which is different than quick weight loss portrayed in the media by fad diets or magic pills. Practitioners also expressed concern that youth want to lose weight to fit in with their friends and have more confidence, but the CHAL program aims to attain these goals by raising self-esteem rather than emphasizing weight loss. Practitioners say they saw a shift in thinking from parents and youth by the beginning of Phase I of the program, in terms of their views behind weight management.

6.1.3 Shared experience

A recurring message that came across from families was the appreciation of shared experiences throughout the program. There was a significant emphasis placed on the relationships formed in the program, and the opportunity to have a dialogue with others who were in similar life circumstances.

Youth took comfort in the discovery that they were not the only ones who were experiencing this condition, and that what was being brought up in group discussions did not apply to them alone. A large success of the treatment program for the youth was the ability to meet new people, make new friends, and relate to other people their own age. They also appreciated that having group discussions and a group approach made the treatment more positive and light-hearted. “The thing I enjoyed the most about group was the funny conversations that would break out at random.” The youth also expressed that “What I like the most is how it seems less [than] a meeting and more of a get-together.” Finally, youth expressed that they did not perceive any judgement from their peers in the program, something which they may have experienced in other parts of their lives.

Parents also echoed the sentiments of the youth, communicating that these shared experiences contributed very much to the positive aspect of the CHAL program. Mothers expressed that the sharing and involvement with other families contributed to them feeling less alone by what their family was going through. “Realizing that we aren’t the only family struggling with this issue.” “To see that our situation is not that unusual.” This was a thought that was shared and expressed by the majority of mothers. Mothers found that simply interacting with other parents in a similar situation gave them a huge sense of support. Mothers also enjoyed receiving tips and suggestions from other parents, on top of the information that was being provided by members of the CHAL team. “Sharing with other parents, listening to suggestions from other parents was very helpful.” Mothers also

expressed that it was beneficial for their children to hear about maintaining a healthy lifestyle from someone other than their own parents.

One mother expressed frustration that at times there was too much time and emphasis put on sharing experiences, taking away from acquiring knowledge from the program staff. "Perhaps better control over the agenda. Some parents get [too] carried away with sharing and we have to rush through content." Also, a few mothers felt that the wide age range of the youth (14-17 years) was detrimental to their child's experience in the group part of the program. "My child said that many of the children were immature (variety of ages). He only found a few children he enjoyed being with each week." Overall, mothers found the shared experiences taken from the program to be mostly positive for themselves and their families.

Fathers generally had the same sentiments towards the shared experiences of the program as the other family members. However fathers held much more importance for the concept of their children hearing about behaviour change from someone other than their parents. "[The program] positively affected my daughter. Hearing information from someone else made her take it more seriously. Some actually sunk in." Fathers expressed that it was comforting knowing that they were not facing this challenge alone, and that there were other families who were also struggling with this issue. They enjoyed the atmosphere and dynamic that was created at the group sessions.

In terms of the practitioners, many expressed that their intervention was group based. The practitioners also mentioned that the social aspect of the program was important for participants to gain other skills. "I think another goal for phase one is also getting them used to the group idea, the idea of them working in a group, a lot of them have a lot of social anxiety, and the idea of going to group and working within a group is pretty scary and so it's an opportunity for them to also just connect with each other and feel more comfortable." Although this idea was expressed by practitioners, there was no

mention from them of how shared experiences affected the parents of youth in the program.

Shared experiences were an essential part of the program experience for youth and their families, and although touched upon by practitioners, did not hold the same weight for practitioners as it did for families. This satisfaction that all of the different types of family members (youth, mothers, and fathers) received from the shared aspect of the program would be a way for providers to entice potential participants into the program. The benefits gained from the shared experience extend to beyond the program, with parents and children gaining increased feelings of confidence and a sense of community from participating in a program where they do not feel stigmatized, but rather supported.

6.1.4 Knowledge

The acquisition of knowledge on management of the condition of obesity, and maintaining healthy lifestyle behaviour was a fundamental theme that emerged from the families and practitioners of the CHAL program.

Youth in the program expressed that much of the information shared by members of the CHAL team during group sessions was beneficial to their understanding of how to manage the condition of obesity. The youth stated that the material was generally presented in a way that was easy to understand, and was applicable to their lives. They also were proud of acquiring this knowledge, and wanted to pass it on to others who were not part of the program. “I learn a bunch of new things that I can teach my friends.”

Parents expressed satisfaction with the knowledge that they acquired from the program, and gave specific feedback on what they took away from these sessions. Mothers

expressed appreciation on covering the topics of diet and exercise, and at having a chance to learn this information from a variety of health care providers. Mothers also appreciated acquiring knowledge about various communication skills that would assist them in speaking with their children. Most mothers communicated that the information was presented in a clear and concise manner and that there was a good balance of theory presented, complemented by the group discussions.

There were various knowledge and skill levels coming into the group sessions, and there was some frustration expressed in terms of the material being covered in the first few weeks of the program. “First 3 weeks (psychologist part) were review for me, ask parents ahead by email or questionnaire what they know, what they want to know offer what CHAL wants & parents want. It was very boring 1st 3-4 weeks learned nothing new from psychologist part, then maybe break into 2 parent groups make it more informative.”

Fathers stated that the information presented was the right amount “I enjoyed the format and found the amount of information right, enough to act [on] but not too much to overwhelm.” Fathers found the medical explanations about the condition of obesity to be informative and helpful; they enjoyed this part of the knowledge that was provided. A few fathers expressed that they would have liked more time spent on interactive activities, and receiving feedback on the activities that their children were doing, so that they had the tools to better reinforce these skills. There was also some frustration from the fathers regarding different knowledge levels. “My [wife] has already done a good job of providing healthy foods in our home, so some of the material was already common knowledge.”

Providers stressed that Phase I of the treatment program is about disseminating a lot of information to the youth and their parents, regarding health behaviours, as well as some psycho-education.

6.1.5 Co-morbidities

Co-morbidities were not a topic that was touched on by the youth or their fathers in any way. Mothers simply expressed that all aspects of obesity were covered during the program.

Providers stressed that associated co-morbidities, including physical and mental health issues were discussed in the program. They also stated that participants in the program struggled with a large range of these conditions. “[Psychologist brought in if] a mental health crisis or there’s binge eating disorder.” “We’ve had a lot of families actually that are challenged in particular by mental health, anxiety, depression, learning disorders, or kids can’t go to school... this population is very challenged because of in particular mental health issues.” Co-morbidities were brought up and discussed by practitioners of the program, however there was almost no mention of this topic by families who participate in the program.

6.1.6 Holistic

There was no mention of the holistic nature of the program by youth or fathers; however, mothers expressed this to be an important part of the program. “I truly appreciated the immediate intervention by [CHAL staff] when a problem arose with my daughter. It gave me the confidence in the holistic approach of this program.” Mothers also expressed that they appreciated the focus of the practitioners on mental health, specifically by changing negative thoughts of the participants to positive ones. The holistic approach of the program is something that was emphasized by providers. “Children live what they see, not what they hear so it’s trying to that whole thinking of that holistic approach that has to be integrated into the whole family to have to change, not just target one individual in the

family incorporate more of that integration.” Practitioners emphasized healthy behaviour with a holistic approach to health. “[H]opefully by the end of the program they’ll be healthier both mentally and physically, with an improved quality of life is our mission. The design of the program focuses on incorporating a number of different elements from different fields, to create a program that addresses all of these different goals.” “A lot of research in terms of other programs out there looks into the evidence, to integrating a number of different fields in terms of creating something we felt would be a good match to our patient population.” These statements encompass the holistic, interdisciplinary approach of the program.

6.1.7 Physical activity

Both acquiring the knowledge and skills for different types of physical activity, as well as participating in physical activity are important concepts of the CHAL program. Youth mentioned that they enjoyed sessions where they did exercise, and wanted more physical activity incorporated into the program. They also mentioned that having a time to exercise together during the sessions was a fantastic way to relieve excess energy that they had.

Mothers mentioned that overall there was an adequate level of knowledge presented regarding physical activity, however they wanted more information on specific principles such as the “FITT” principle (Frequency, Intensity, Timing, Types) (Oberg, 2007). A desire was also expressed for more information and skills on how to motivate children to exercise, who did not want to do so, or did not have the ability to participate in organized sport. Mothers also wanted strategies on physical activity that could be done with their children, and they would have liked the opportunity to exercise with their children as part of the program. There was a clear expression of interest for organized opportunities for

mothers to participate in activity with their children. One mother expressed the belief that obstacles to physical activity were clearly identified in the program, but solutions less so.

Fathers expressed observing some positive behaviour change in their children in terms of physical activity as they progressed through the program. Fathers also expressed a positive attitude towards the focus of the program being away from dieting, and rather having more of an emphasis on physical activity. Some fathers wanted more strategies on incorporating physical activity into the lives of their families, and specifically wanted a continuum of exercises that could build on the strategies that they learned during the program.

Providers focused on physical activity as behaviour that participants and their families had control over, and the importance of emphasizing this during the program. Providers stated the importance of giving participants the tools and knowledge to change their physical activity behaviours in a positive manner. “[W]hether they need help figuring out what to do at the [gym] they want to go to the gym but don’t know what to do.” Providers also expressed that behaviour change in terms of physical activity was a goal and outcome measure of the program. “Those are goals that we set or that changes in health behaviours because that’s... about the only thing you have control over. Any change in a health behaviour whether it’s physical activity related or food related, or if it’s mental health related, any changes that they make in that, that’s what we’re focusing on and [that’s] where measures of success we would look for it to be.” Increase in physical activity was an important behaviour change for families of the program, as well as practitioners.

6.1.8 Healthy food

Education and skill development around healthy food habits and behaviours are another main component of the CHAL treatment program. Youth, families, and providers all shared beliefs on the importance of these skills.

Youth in the program expressed that they enjoyed learning about healthy food habits, in particular the concept that “you don’t have to be skinny to be healthy” and tips around portion sizes. Youth also expressed a desire to learn more about food, and wished that recipes were shared with themselves and their parents.

Mothers expressed receiving information on healthy food and eating behaviours, and appreciated the advice regarding a hands-off approach “No nagging about weight, exercise, food!” regarding their children. Mothers also wanted more information on meal planning, and expressed hope that the information provided would help to foster more healthy food habits in their families.

Fathers expressed already seeing some positive changes in their children’s healthy food habits. Fathers enjoyed the discussions surrounding food, and one father expressed gratitude for the snacks provided by staff members of the program.

Providers stated that part of the treatment program included presenting nutrition information to parents and youth. They focused on “weight maintenance in cooperation with more healthy lifestyle aspects” and helped participants set healthy food behaviour goals. Providers also expressed that specialized services were provided for patients with eating disorders such as binge eating. These patients were given more intensive treatment with psychologists for this condition.

Overall, healthy food behaviours were identified to be an important aspect of behaviour management, by both families and providers.

6.1.9 Family

The role of family is integral in treating the condition of obesity in adolescents. Youth, family members and providers all stressed the importance of having family involved in this process.

Youth expressed a desire to have even more family involvement in the program. They expressed a desire for parents to see what they were doing in their group sessions, and to get their parents more involved in this aspect. They wished to have more opportunities for parents and youth to collaborate during the program. There was also a desire by many to have their siblings involved in some way with the program.

Mothers also expressed a desire for other siblings to be involved in some way in the program. They echoed the youth's sentiments of having more time to participate with parents and youth together in group sessions. Mothers suggested doing this through exercise, or discussion. Mothers also felt that they should be told what their children were going in the youth part of the group therapy.

Fathers enjoyed the open discussions surrounding family dynamics which took place during the group sessions.

Providers stressed the importance of having parents actively involved in the program. "It's not just the child but it's the whole family [that] needs to work together as a team to make change." Providers encountered resistance from some parents who did not

see the importance of active participation and behaviour change. “That’s where we run into a bit of differences of we’re asking parents to set goals and they might think you know, I’m here for my kid why am I having to change kind of thing.” Providers also expressed concern that while mothers regularly came out and participated in the program, it was often more difficult to have fathers involved. They expressed that they felt this was a work in progress. This may be due to a variety of factors including many single mothers participating in the program, and the hours of the active treatment session not being compatible for fathers who did want to be involved in the program. This second barrier may be mitigated in the future as the program grows, by offering sessions when it may be more convenient for fathers to attend, such as on the weekend.

The family aspect of the CHAL program is an essential focus, to have behaviour change not only from the youth who has the condition of obesity, but from the whole family who has a huge impact on lifestyle behaviour.

6.2 Themes and formal program goals

The data from the youth, mother and father questionnaires, as well as the data from the provider focus groups gives insight to the view of each party in terms of the CHAL program treatment. The themes arising from the data correspond in different ways to the formal goals of the program, and provide insight of the views of these parties with relation to the strengths, gaps, and potential recommendations that they have provided. The views of the patients, families, and providers are examined with regards to the formal goals of the program.

6.2.1 Improve quality of life

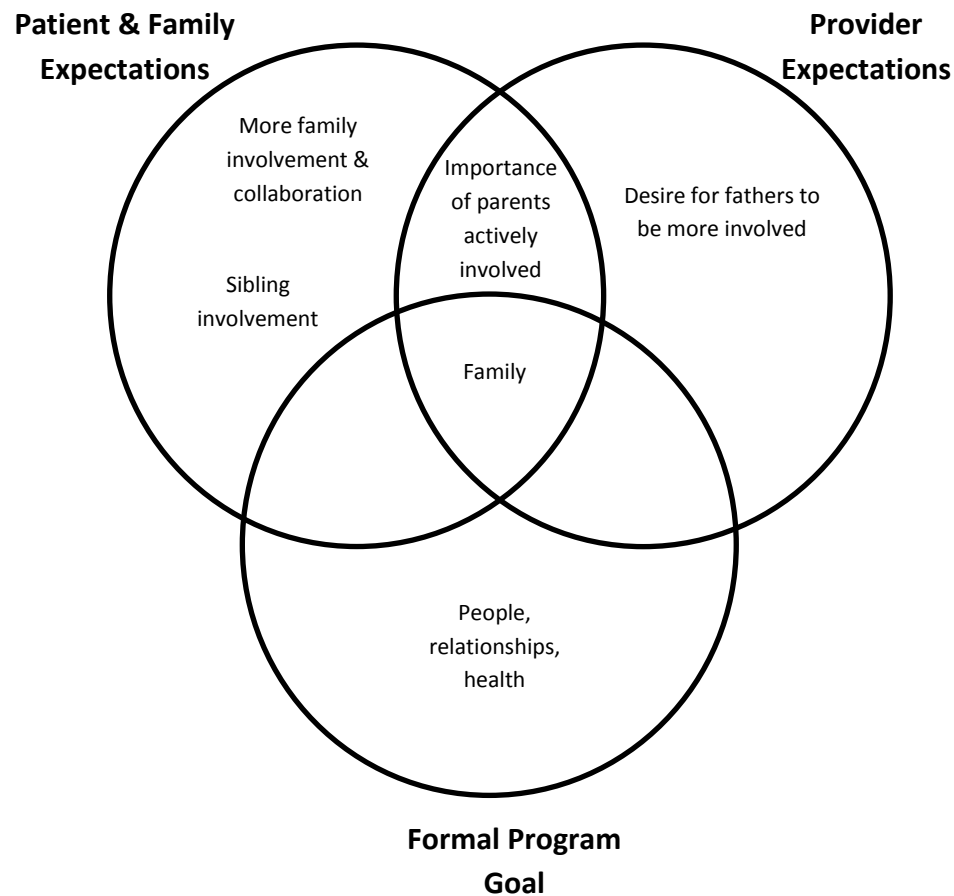


Figure 5. Comparison of patient and family expectations, provider expectations, and CHAL formal program goal: Improve quality of life.

The goal of improving quality of life applies to not only the patients of the program, but to their families as well. Childhood obesity impacts the quality of life of all family members; as well, the behaviour changes that are part of the treatment program are expected to be made by all family members in order to work towards this goal. The theme of “family” addresses the formal program goal of improving quality of life. Youth suggest that the program gives an opportunity for parents and their children to collaborate, fostering a stronger relationship through shared activities of the program. This aspect helps to improve quality of family relationships. According to fathers, this also brings forth an opportunity to have a discussion surrounding the dynamics of the family.

Both youth and mothers expressed a desire for sibling involvement in the program. This is a gap which exists for mothers and youth, which would benefit by providers addressing the reason siblings are not involved, during an information piece of the program.

6.2.2 Decrease medical and psychological co-morbidities

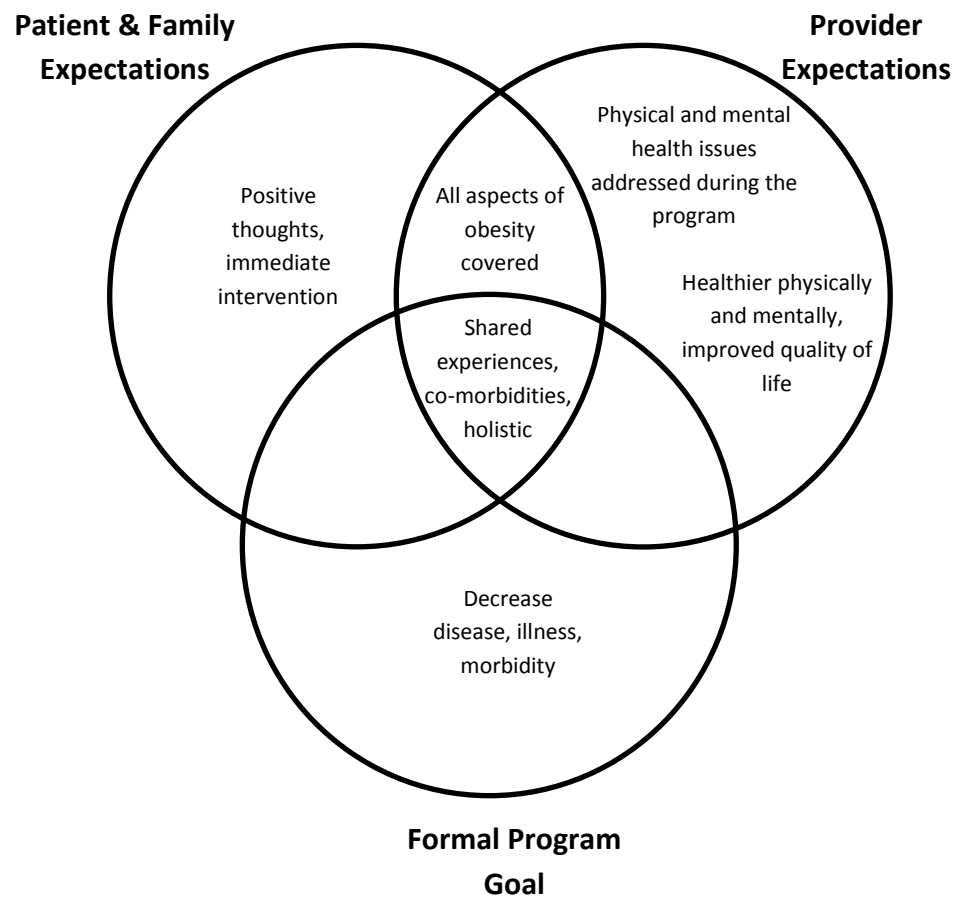


Figure 6. Comparison of patient and family expectations, provider expectations, and CHAL formal program goal: Decrease medical and psychological co-morbidities.

The formal program goal of decreasing medical and psychological co-morbidities in youth who are being treated at the CHAL program was a goal which was addressed through two themes that came up in the data: “co-morbidities” and “holistic”.

The views from the participants and their families show that reducing co-morbidities did not reflect as a priority for them when they gave feedback with regards to the CHAL treatment program. Mothers expressed that all aspects of obesity were covered during the course of the treatment; however there was no mention of co-morbidities by youth or fathers of the program. Similarly, mothers mentioned the importance of the holistic nature of the program, but this was not focused on by youth or fathers. Practitioners stressed the importance of focusing on improving physical and mental health, including addressing issues surrounding associated co-morbidities during the program.

A gap exists for addressing the co-morbidities for youth and their fathers. For youth, perhaps they are concerned with items that have a more immediate impact on their lives. With regards to fathers, practitioners have brought up the concern that while mothers are very involved in the program, they would like to see more involvement from fathers; potentially this is where the gap lies in the understanding of fathers of the importance of addressing the impact of co-morbidities on their children who are living with the condition of obesity.

6.2.3 Improve eating behaviours

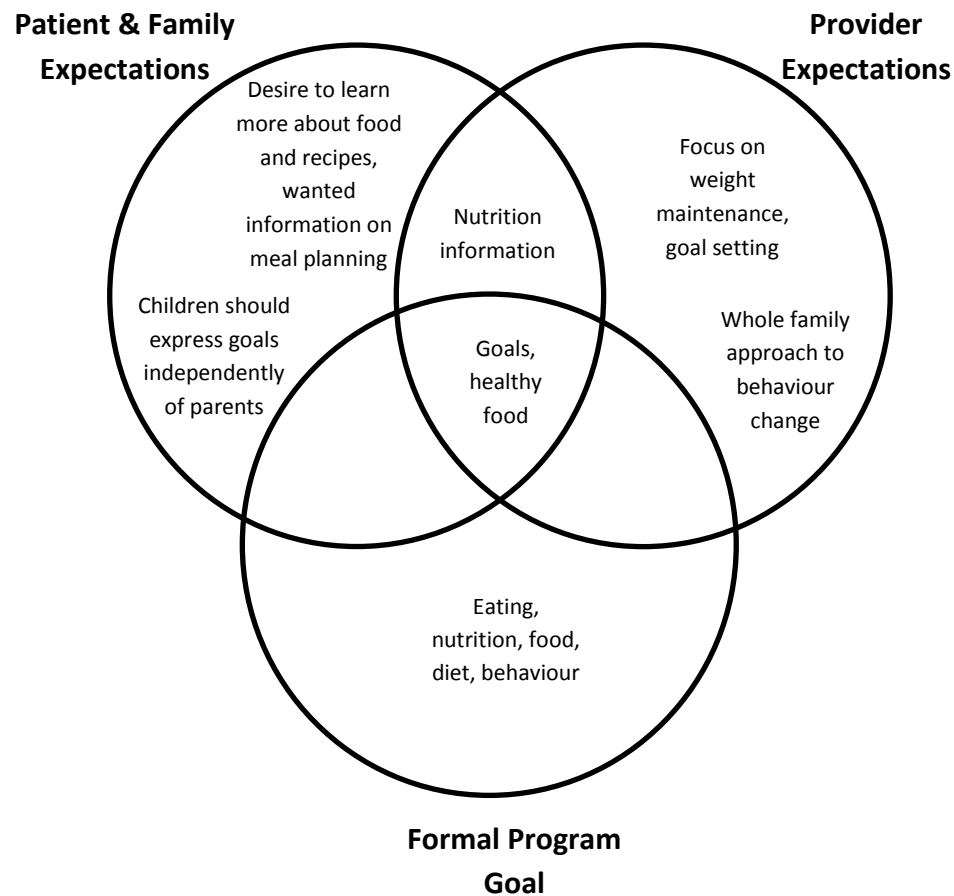


Figure 7. Comparison of patient and family expectations, provider expectations, and CHAL formal program goal: Improve eating behaviours.

The third formal goal of the program, improving eating behaviours, was one which was addressed through two themes that came up in the data gathered from the questionnaires and the focus group: “goals” and “healthy food”.

While practitioners mentioned that presenting nutrition information was a focus of their strategy, this did not seem to fully reflect the importance that was put on this topic by youth and their parents. Youth took to heart the goal of trying to improve their healthy eating behaviours, by absorbing the tips on healthy portion sizes, expressing a desire to

learn more, and have more food advice and recipes. Mothers also expressed appreciation of the skills and information disseminated around this topic. Fathers expressed that they were already seeing some behaviours change for their kids in this regard. Both families and practitioners expressed through their views that the goal of improving eating behaviours was an important one, and that they were taking active steps towards achieving this.

6.2.4 Improve fitness, increase activity levels

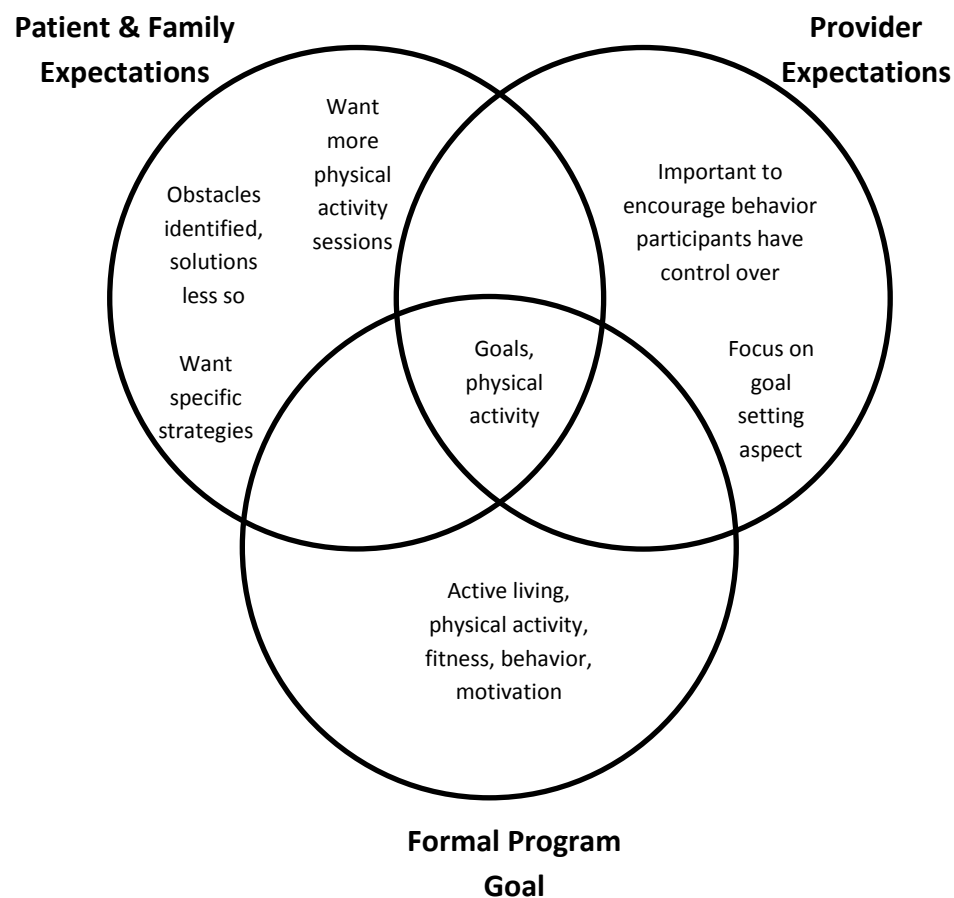


Figure 8. Comparison of patient and family expectations, provider expectations, and CHAL formal program goal: Improve fitness, increase activity levels.

The formal program goal of improving fitness and increasing activity levels was also one which was alluded to through two themes that came up from family and practitioner views. The “goals” and “physical activity” themes addressed the importance of improving fitness and increasing activity levels of the participants in the program from the perspective of the practitioners and the families.

The practitioners of the program identify that physical activity is a behaviour that participants have control over and that is was important for them to encourage this positive behaviour change. For the families however, physical activity was a major cornerstone of the program, and families had strong views when it came to this formal program goal. Youth expressed that the physical activity sessions helped them to relieve excess energy. This most likely lead to them having an easier time concentrating during the group sessions and gave them a greater ability to absorb information. Youth, mothers and fathers all expressed a desire for more opportunities and skills regarding physical activity. This formal goal of the program was very important for all family members, and this importance should be stressed to practitioners, in order for them to have a greater understanding and appreciation of their population’s needs. This emphasis by participants and their families could be perhaps that they see physical activity as a concrete, tangible way to assert control over an aspect of their weight management, whereas in other areas such as decreasing sedentary activity, they may find more difficult to strive towards and may not be able to meet because of other demands in their lives, such time spent on the computer for work and school.

6.2.5 Decrease sedentary behaviour

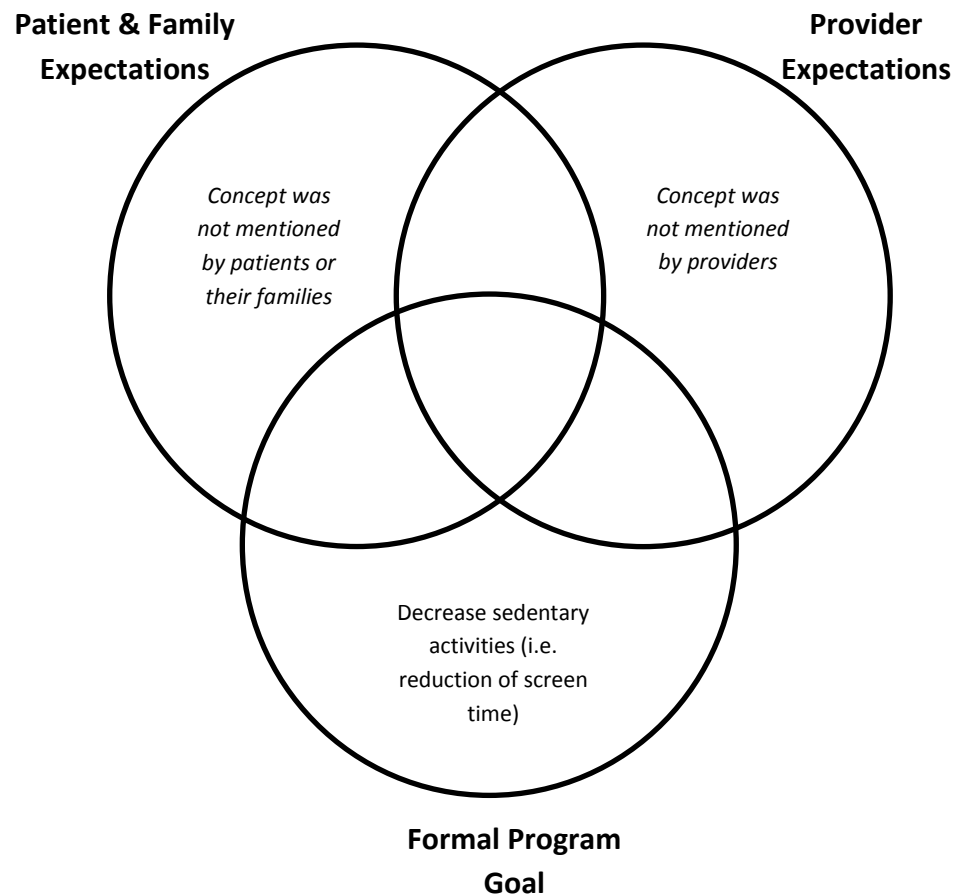


Figure 9. Comparison of patient and family expectations, provider expectations, and CHAL formal program goal: Decrease sedentary behaviour.

The formal program goal of decreasing sedentary behaviour is complementary to the goal of improving fitness and increasing activity levels; when progress towards one of these goals is achieved, by nature there is also progress made towards the other goal. With this in mind, this goal was touched on through the views on physical activity, by families and practitioners. However, progress towards this goal was not explicitly stated; it was just implied with progress toward the goal of improving fitness and increasing activity levels. For

explicit views regarding this goal, references would have to be made towards actively trying to reduce sedentary behaviour, such as time spent on screen activities (computer, television, video games). There was no mention of concepts relating to this formal goal by any of the parties.

6.2.6 Empower/strengthen families

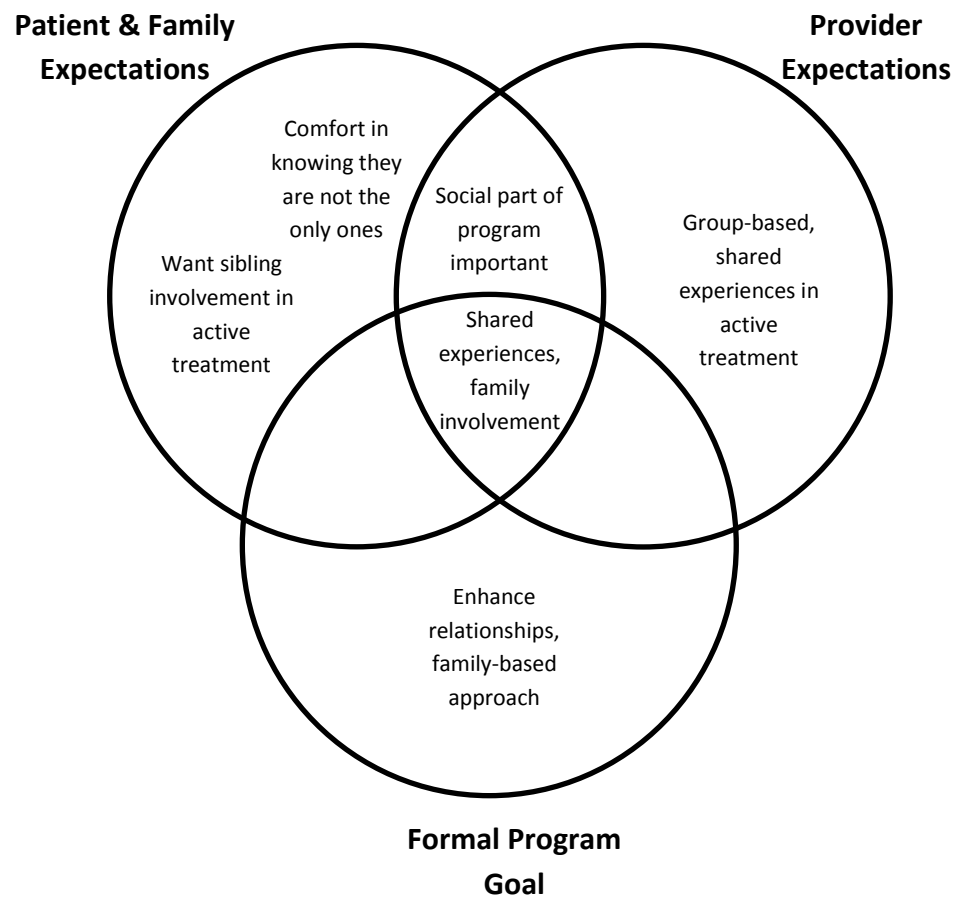


Figure 10. Comparison of patient and family expectations, provider expectations, and CHAL formal program goal: Empower/strengthen families.

The formal program goal of empowering and strengthening families was addressed by the views of the families and the practitioners, and expressed through two themes which emerged from the data: “shared experience” and “family”. The practitioners of the program shared that the treatment parts of the program were group based, and there was a social part to the program; however, this did not capture the essence of how important this was to the families. From the perspective of the youth and their parents, the support and time for shared experiences were one of the main advantages and successes of this program. The group sessions provided a safe forum for discussion, and opened up the notion to families that they were not the only ones dealing with this problem. This lifted some of the stigma felt by families and relieved some of the social isolation that was felt by youth who had the condition of obesity. The practitioners also acknowledged the importance of having parents actively involved towards the treatment of their children in the program. They stressed the importance of having fathers involved; they believed this to be a gap in some instances when there was less active involvement in the treatment by fathers.

Family members expressed the desire for even more family involvement, specifically when it came to having siblings involved in this process. This is a gap identified by youth and their mothers; they believed that it was important for the whole family, including siblings, to be involved in the active treatment and behaviour change components of the program.

6.2.7 Stabilize BMI trajectory

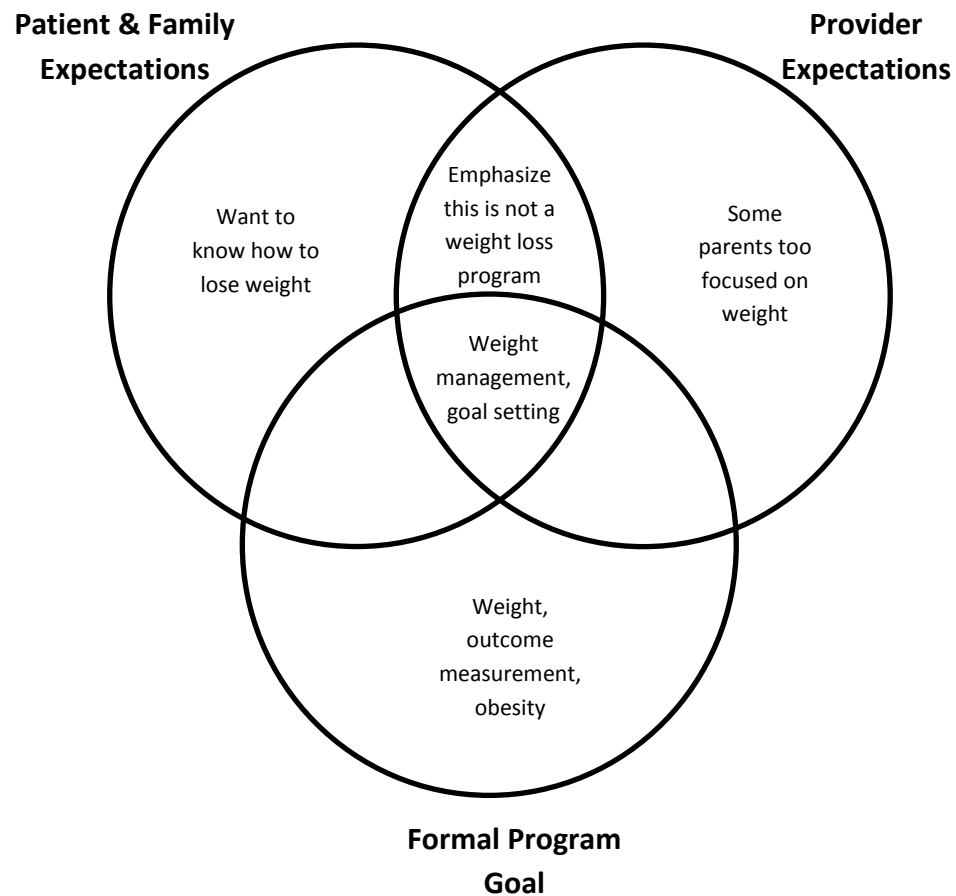


Figure 11. Comparison of patient and family expectations, provider expectations, and CHAL formal program goal: Stabilize BMI trajectory.

Stabilizing BMI trajectory was a goal expressed by participants and practitioners in terms of “goals” and “weight”, when speaking about their views. Practitioners and parents alike stressed that CHAL was not a weight loss program; however there was no explicit mention of stabilizing BMI as a desired goal or outcome.

Providers expressed frustration that many patients and their families came into the program expecting a weight loss program. From the views of youth and parents, even if this

was initially the case, this view was no longer held after taking part in an active treatment phase of the program. For the most part, youth and parents were in agreement that CHAL was not a weight loss program, however there was no mention of stabilizing BMI as a goal.

6.2.8 Potential program goals

Potential program goals arose from views that were expressed but not explicitly captured by any one CHAL formal program goal. A main topic which both family members and practitioners mentioned repeatedly was that of knowledge. “Knowledge” was one of the themes identified from the data that was collected. Practitioners mentioned that disseminating information regarding health behaviours and psycho-education was a large piece component of the program; this also helped to support other program goals. For families, the topic of knowledge was one of great importance. Youth indicated that the knowledge they received was highly valuable to them, so much so that they wanted to pass this information on to other peers who were not part of the CHAL program. Parents also expressed that the knowledge they received was very useful; at times there was frustration at the simplicity of topics presented, but all parents agreed that the information disseminated was very useful.

7. Discussion

7.1 Current study fit

Although various obesity evaluation frameworks of clinical obesity programs exist, there are none which examine the alignment of views between patient and provider expectations. In the spectrum of evaluation frameworks, figure 12 demonstrates the fit of this current study.

Clinical outcome and efficiency	<i>Health care utilization from prevalent medical conditions in normal-weight, overweight, and obese children.</i> (Kirk et al., 2012).
	<i>Tackling inequalities in obesity: a protocol for a systematic review of the effectiveness of public health interventions at reducing socioeconomic inequalities in obesity amongst children.</i> (Bambra et al., 2012).
	<i>Service quality and attrition: an examination of a pediatric obesity program.</i> (Cote et al., 2004).
	<i>Scopes, limitations and satisfaction in managing childhood obesity in primary and secondary healthcare services' time for improvements.</i> (Dhorajiwala et al., 2010).
	Current study <i>Using path analysis to understand parents' perceptions of their children's weight, physical activity and eating habits in the Champlain region of Ontario.</i> (Adamo et al., 2010).
Patient satisfaction	<i>Factors associated with parental readiness to make changes for overweight children.</i> (Rhee et al., 2005).
	<i>Parents' perceptions of their child's weight and health.</i> (Eckstein et al., 2006).

Figure 12. Fit of current study on clinical obesity program evaluation frameworks spectrum.

7.2 Summary of results

From the data that was obtained through the questionnaires administered to families, and the focus group data that was collected, the following recommendations may be concluded with regards to the formal treatment goals of the CHAL program. These recommendations may be applied to this and similar obesity management programs.

In terms of the first formal program goal “improve quality of life” there was desire expressed by both youth and their mothers to have siblings of youth who are enrolled in the CHAL treatment program to have some participation in the active treatment part of the program. This view must be acknowledged by providers, and discussed appropriately with youth and parents alike. The second recommendation includes a greater emphasis put on addressing co-morbidities and a holistic approach by practitioners of the program. This would help to ensure that the message reaches the population that is being targeted by this active treatment plan. Emphasizing that the effects of co-morbidities may be irreversible may help youth to take a more diligent approach to their obesity management regime (Lau et al., 2007).

The goals of “improve eating behaviours” and “improve fitness, increase activity levels” were of very high importance to families; this should be brought to the attention of practitioners so they are able to understand and reflect on the needs of their group. Furthermore, more opportunities for organized sport and a continuum of these activities should be established in order for families to succeed in achieving and maintaining increased physical activity levels. Along with this, practitioners should encourage explicit strategies towards the goal of “decrease sedentary behaviour” by encouraging the reducing of screen time. This could be done through educating parents on setting limits for screen time, as this has shown to be an effective method of decreasing sedentary behaviour for youth (Carlson et al., 2010).

More emphasis should also be placed on the shared experience when explaining the benefits of the program; although “empower/strengthen families” is an explicit goal, the amount of importance this has for all family members may be missed by practitioners if not reiterated. The goal of “stabilize BMI trajectory” should also be explicitly stated if it is a formal program goal; there was little emphasis placed on this by family members.

Finally, themes arising from families should be explored for the possibility of developing new formal program goals. The sharing and gathering of knowledge was extremely important for youth and parents alike, and would benefit this knowledge sharing to be officially recognized so that the achievement of acquiring knowledge is formally valued by CHAL staff.

7.3 Limitations

The results from this study must be taken into consideration with regards to the context in which they fit and the limitations attributed to this study. The limitations which apply to this study include limitations regarding data collection tools, classical limitations of qualitative analysis and case study format, as well as limitations of respondent bias.

7.3.1 Data collection tools

The main limitation of this study was the tools that were used to collect data for the examination of the research questions. The tools used hampered the ability of the researcher to thoroughly examine the stated research questions.

The REAL program feedback forms gave limited opportunity for youth and parents to provide their feedback in terms of their experience of the program. This feedback was limited to a few lines per question, with only two questions “What did you find most useful about the group sessions?” and “Do you have any suggestions to help make the group sessions more useful to families?” providing any type of opportunity to give feedback on program content. The other two questions gave an opportunity to provide logistical feedback and other comments (Appendix B). This tool was not designed to elicit comprehensive feedback from the parents or their families about the formal goals of the program.

As well, the use of two different methods of data gathering (questionnaires and focus group discussion) for the two sets of respondents decreases the rigour of the analysis.

7.3.2 Qualitative analysis limitations

Qualitative analysis limitations apply to this study. “...data are not usually immediately accessible for analysis, but require some processing.” (Miles & Huberman, 1994, p. 9). Such processing includes transcription of tapes, which is subjected to some interpretation from the transcriber. Also, the concepts and coding that emerge from the transcribed data of both the patient questionnaires and focus group interview are subject to interpretation of the researcher (Miles & Huberman, 1994). This limitation can be mitigated by using a second person to transcribe, independently code the data and discuss any disparities. A limitation of the focus group design is the use of open-ended responses that might be difficult to categorize, and possibility that opinions presented by assertive members may overwhelm ideas of the rest of a group.

7.3.3 Case study format

The study was conducted at one location, making the results difficult to generalize to other programs.

7.3.4 Respondent representativeness

Patients/parents attitudes will be discovered using an existing study instrument. Due to the secondary character of data analysis, the researcher did not have control over data collection. As indicated in the CHAL patient flow diagram (Figure 4), the REAL Program Feedback Form (Appendix B) is administered to youth and/or parents once they have completed each phase of the program. As a result, this data only shows the viewpoint of participants who have completed an active part of the program. This does not give the point of view of those who only participated in assessments, or who declined to participate in the program. The data also does not allow identifying of the reason some patients have not progressed to the next phase of the program. It could be that the patients/parents declined to participate in the next phase because they were not satisfied, were waiting to be enrolled, or had logistic problem (lack of transportation, inconvenient times, etc.). Thus, a main limitation here is that survey data relates only to patients/parents who have enrolled in the active treatment part of the program and it is not possible to explore views of those who decided not to be part of it.

7.4 Program recommendations

The following program recommendations are made after taking into consideration the limitations of the current study, best practices identified in the literature, and recommendation identified from analysis of the questionnaire and focus group data.

7.4.1 Instrumental

For providers of the program to gain a more comprehensive approach to studying the experiences of youth and their families in the program, an instrument which is more appropriate in assessing these responses should be used to gain a more accurate reflection of their views. A similar approach can be found in the study “Conversations on psoriasis- what patients want and what physicians can provide: A qualitative look at patient and physician expectations” by Uhlenhake, et al. (2010). This study aims to examine the views of patients and providers in the context of psoriasis treatment. The data collection process involved, namely discussion group sessions, would be the ideal way to study the views of patients and their parents in the context of a clinical obesity treatment program.

7.4.2 Procedural

The timing in which feedback forms are administered is also essential. At this point in the program, feedback is collected at the end of the active treatment phase (see Figure 3- CHAL patient flow diagram, and Table 2- CHAL outcome measures taken at each time point). Although many outcome measures and assessments are taken at various points in the program, it would be beneficial for a mid-active treatment assessment to take place, in order to determine at that point whether the views of all parties are aligned. This would help to address any concerns early on, such as program content being too basic for some

participants, or participants wanting more focus on a particular issue that was important to them, such as decreasing barriers to participating in physical activity.

7.4.3 Systemic

The CHAL program addresses an issue which is influenced by many components of an individual's life. The participants in the program are not encountering the treatment part of the program in a vacuum. Youth are constantly bombarded with interactions in their daily lives, which would hinder or complement their progress in the program, depending on how these items are addressed. Figure 13 shows the potential data collection points system wide to enhance data in terms of evaluating future effectiveness of the program.

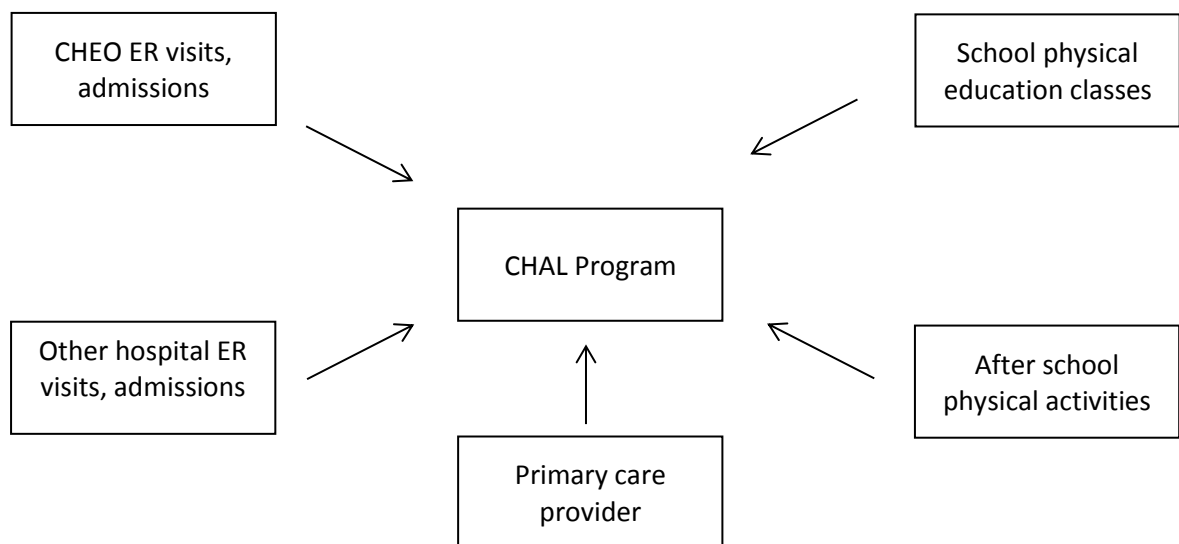


Figure 13. Potential systemic points of data collection for CHAL program.

Inputs from CHEO and other hospitals on visits and admissions would generate data related to patient co-morbidities and overall morbidity. This tracking of visits over time may lead to information for CHAL program staff on the effectiveness of their intervention in decreasing morbidity. Difficulty of this would include compatibility of electronic systems for data compilation. This may be more feasible to achieve with data from CHEO, as the system may already be compatible.

Although youth are participating in the treatment process at CHAL, they typically remain in contact with their primary care provider; this is usually the person who referred them to the program. One of the main complaints of primary care physicians when dealing with clinical obesity programs is that they are not given information, or they are neglected once the patient starts the treatment process of the clinical obesity management program (McClaskey, 2010). Clinical obesity management programs such as CHAL should use this resource to their advantage to help provide support to the youth and their family as often, this relationship with the primary care provider is an ongoing one, and could be a source of support for the youth and their family in the future. Data from primary care providers would assist with the gathering of clinical measures, and would help primary care providers feel more engaged with the clinical obesity management process of their staff. Barriers to implementation include compatibility of systems, and willingness of primary care physicians to participate with assessment of measures and data recording.

The program could also link with other components of the youth's life such as physical activity programs in schools to help maintain some of the behavioural outcomes that they are looking to change during the treatment phase of the CHAL program. Measures such as the number of physical activity classes that a youth participates in would add data to behaviour change measures which is less likely to be biased, as it would not rely on self-reporting from the youth or their parents. There would be even greater barriers to face in terms of complexity of data collection, as finding a system which would be able to compatibly send electronic data to CHAL's records would be highly improbable. The

advantages would be however, that this data is already electronically inputted by teachers at most schools for attendance tracking purposes. This would be a useful measure as often, youth who experience the condition of clinical obesity do not participate in physical activity, and their participation may indicate behaviour change.

Similarly, inputs from after school physical activity programs would presumably indicate even greater behaviour change, as this behaviour would not require mandatory participation, such as may be the case with school physical education classes. However, the gathering of data would be even more complex, as currently there are usually no electronic systems to track this, and tracking may even not occur with such activities. For this instance, it may serve to rely on patient or parent self-reporting, but with predetermined measures to collect (ex. number of hours spent participating in organized physical activity).

These systemic sources of data collection have varying layers of complexity in their potential implementation. Table 6 summarizes the level of complexity, associated barriers with each potential data source including probability of data collection system compatibility.

Potential data collection source	Barriers to implementation	Data collection system compatibility
CHEO ER	Data collection system	Probable
Other hospital ER	Data collection system	Potential
Primary care provider	Data collection system Provider willingness	Potential
School physical activity classes	Data collection system	Unlikely
Other organized physical activities	Data collection system No current tracking processes	Highly unlikely

Table 6. Summary of potential data sources, their associated barriers, and probability of data collection system compatibility, from least to greatest complexity of implementation.

7.4.4 Conceptual

Theoretically, patient centered care is the most appropriate framework applied to a behavioural therapy program. However, in reality there are many stakeholders whose views must be taken into consideration. The continued approach of considering the views of patients as stakeholders alongside practitioners will help to drive the formal goals of the program to have a more patient centered focus.

The current approach of the CHAL program feedback process seeks to measure the outputs of the program, rather than evaluating the overall outcome. Outputs are measures such as the number of patients who have been treated by the program, the clinical data

which is gathered during the patient assessments, and the current type of feedback which is solicited from patients of the program, and their parents. To capture the outcomes of the program, an evaluation on whether or not the patient, or the population as a whole is becoming healthier should be conducted. The CHAL mission is: “To provide a comprehensive, coordinated, family-based treatment approach for children and youth with complex severe obesity requiring sub-specialized medical care.” (Children’s Hospital of Eastern Ontario, 2012). Although the mission is achieved through the overall delivery of the program, there is no method of measuring, through current data collection methods, the effect of the treatment program on overall health of the individual or the population as a whole.

To aid with overall compliance of the program, feedback collected specifically to examine the alignment of formal programs goals with patient, family, and provider expectations of the program would be greatly beneficial. The more the goals of the patients and their parents are aligned with the provider goals and the formal goals of the program, the greater the likelihood of program attendance and compliance.

8. Conclusion

While the Centre for Healthy Active Living at the Children's Hospital of Eastern Ontario addressed many of the important aspects in the views of patients and their families, there are specific areas which may be enhanced to gain greater alignment with the views of these participants. Including siblings in part of the active treatment phase of the program would help to address concerns relating to the "improving quality of life" goal. Adding more practical information, resources, and tools to the topics of healthy eating and physical activity would improve participants' behaviour changes to gain greater alignment with the "improve eating behaviours" and "improving fitness, increase activity level" goals. The shared experience of participating in the program with other families who were in a similar situation was of huge importance to all participants- formalizing this component alongside the "empower/strengthen families" goal would be of great importance. Finally, acquiring knowledge was something which was of great importance to families, and so far this is not explicitly stated with any of the existing formal goals. Recommendations provided with regards to instrumental, procedural, systemic, and conceptual components of the CHAL program would assist in the further development and expansion of the program.

Future studies on the topic of clinical obesity programs geared towards children and youth would benefit from exploring the topics of economic evaluation, sustainability of programs, and long-term follow up of patients who have participated in a clinical obesity management program during their youth.

Behaviour therapy programs such as clinical obesity management programs would gain compliance, thereby increasing rates of success of their program by having a comprehensive method of eliciting feedback from patients, their families and providers in terms of their expectations of the program.

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Appendix A- Ethics Approval

RETROSPECTIVE CHART REVIEW AND SECONDARY ANALYSES OF CLINICAL DATA – CONT'D		
My signature confirms that, as Primary CHEO site investigator: • I assume full responsibility for the research as outlined in this application. • I will comply with the previously mentioned privacy and confidentiality conditions. • The personal health information collected in this study will: 1. Be used only as necessary, to fulfill the specific research objectives and related research questions described in this application and approved by the REB. 2. Be encoded in a way that would not be identifying of the individual. Codes based on date of birth, ethnicity, and residency will be avoided. Variables that can be identifying of the person either alone or in combination will similarly be avoided. 3. Be stored in locked areas and access will be restricted to the names listed above. Any personal health information that leaves the site for any reason will be de-identified, password protected and encrypted. Data will be destroyed at the conclusion of the study. 4. Not be used to contact or attempt to contact the patient whose personal health information is being researched unless CHEO first obtains the patients' express written consent. 5. Not be published in a way that could reasonably allow others to identify the patient whose personal health information is being researched. 6. Immediately notify the REB in writing if the investigator becomes aware of any breach of confidentiality or security. 7. Be disclosed except as required or permitted by law.		
Signed:	Primary CHEO Site Investigator Print Name: Research Assistant Print Name:	April 2/12 Date: April 2, 2012 Date:
<i>Unless otherwise indicated by the investigator, the CHEO REB will assume that the study will be concluded within a year of this approval date. If the investigator requires a longer activation period, an annual renewal report should be filed with the Board.</i>		
Please forward to: Mrs. Natalie Anderson, Administrative Assistant Research Ethics Board Children's Hospital of Eastern Ontario Room R250E, 401 Smyth Road, Ottawa, Ontario, K1H 8L1 Telephone: (613) 737-7600, ext. 3350		CHEO Research Ethics Board – APPROVAL Chair's Signature: Date: <u>April 16, 2012</u>

Signatures removed to comply with thesis technical standards.

Appendix B- REAL Program Feedback Form



CENTRE FOR HEALTHY
ACTIVE LIVING
LE CENTRE DES SAINES
HABITUDES DE VIE

**R.E.A.L. Program: Phase I
Feedback Form**

1) What did you find most useful about the group sessions?

2) Do you have any suggestions to help make the groups sessions more useful to families?

3) Were the group sessions offered at a time (6:16pm-8:15pm) that worked well for you and your family? Is there a time that would have worked better?

General Comments:

Thank you!

Appendix C- Participant Consent Form

Consent Form

Title of the study: **The study of alignment of patient and provider attitudes in health care intervention programs: A qualitative case study of the Centre for Health Active Living at the Children's Hospital of Eastern Ontario**

Asha Gajaria
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Invitation to Participate: I am invited to participate in the abovementioned research study conducted by Ms. Asha Gajaria, a graduate student at the Telfer School of Management, University of Ottawa under the supervision of Professors Wojtek Michalowski and Raywat Deonandan.

Purpose of the Study: The purpose of the study is to determine if there is a positive association between participants' attitudes towards a lifestyle changing intervention, and the program's outcomes. The study will also examine the relationship between provider expectations, and the perceived experience of the participants.

Participation: My participation will consist essentially of participating in a semi-structured focus group that will last approximately 1 hour.

Risks: My participation in this study will entail that I describe my role and general understanding of the CHAL program. No personal information will be revealed during the interview. Data collected from the interview will be kept in a secure location only accessible by the researcher.

Benefits: My participation in this study will help to understand how the CHAL program functions in order to contribute to further study examining the attitudes of children and their parents who participate in the program.

Confidentiality and anonymity: I have received assurance from the researcher that the information I will share will remain strictly confidential. I understand that the contents will be used only for the researcher to gain a better understanding of how the CHAL program works and that my

confidentiality will be protected by keeping the data in a secured location. The interview participants will not be identified in the study.

Conservation of data: The data collected by tape recording of the interviews and free text notes by the researcher will be kept in a secure manner under lock and key in a location only accessible by the researcher. The data will be kept for the duration of the thesis research project and thereafter destroyed.

Voluntary Participation: I am under no obligation to participate and if I choose to participate, I can withdraw from the study at any time and/or refuse to answer any questions, without suffering any negative consequences. If I choose to withdraw, all data gathered until the time of withdrawal will not be included in the study, and will be destroyed.

Acceptance: I, _____ agree to participate in the above research study conducted by Asha Gajaria of the Telfer School of Management, University of Ottawa, under the supervision of Professors Wojtek Michalowski and Raywat Deonandan.

If I have any questions about the study, I may contact the researcher or her supervisor.

If I have any questions regarding the ethical conduct of this study, I may contact the Protocol Officer for Ethics in Research, University of Ottawa, Tabaret Hall, 550 Cumberland Street, Room 154, Ottawa, ON K1N 6N5
Tel.: (613) 562-5387
Email: ethics@uottawa.ca

This study has been reviewed and approved by the CHEO Research Ethics Board. The CHEO Research Ethics Board is a committee of the hospital that includes individuals from different professional backgrounds. The Board reviews all human research that takes place at the hospital. Its goal is to ensure the protection of the rights and welfare of people participating in research. The Board's work is not intended to replace a parent or child's judgment about what decisions and choices are best for them. You may contact the Chair of the Research Ethics Board, for information regarding patient's rights in research studies at (613) 737-7600 (3272), although this person cannot provide any health-related information about the study.

There are two copies of the consent form, one of which is mine to keep.

Participant's signature:

Date:

Researcher's signature:

Date:

Personal information removed to comply with thesis technical standards.

Appendix D- Focus Group Questionnaire Guide

Focus Group Guide

The purpose of the focus group is to collect data regarding providers' attitudes. The format of a focus group will also allow data to be collected about the providers' expectations with regards to patients/parents experience.

- The focus group will take place during a regular team meeting.
- The focus group will last approximately 45 minutes in duration.
- Participants include:
 - Endocrinologist
 - Clinical Psychologist
 - Registered Dietician
 - Exercise Specialist
 - Nurse-Case Manager
 - Child & Youth Counsellor
 - Administrative Assistant
 - Research Coordinator

The open-ended topics to be addressed include:

- 1) What is your role at CHAL?
- 2) What are the components of this program? What does each component achieve? (What is the goal?)
- 3) In your view, what are the expectations of the parents?
- 4) How did you come to this inference? (Why do you believe these are the expectations? On what basis?)